

Disability rights during the pandemic

A global report on findings of the COVID-19 Disability Rights Monitor



DISABILITY RIGHTS INTERNATIONAL



International
Disability
Alliance



Centre for
Human Rights
UNIVERSITY OF PRETORIA

VALIDITY



Credits

© COVID-19 Disability Rights Monitor 2020

Lead author: Dr. Ciara Siobhan Brennan

Editors: Steven Allen, Rachel Arnold, Ines Bulic Cojocariu, Dragana Ciric Milovanovic, Sándor Gurbai, Angélique Hardy, Melanie Kawano-Chiu, Natasa Kokic, Innocentia Mgijima-Konopi, Eric Rosenthal, and Elham Youssefian.

Design and accessibility by Stafford Tilley
www.staffordtilley.co.uk

Disclaimer

This work may be freely disseminated or reproduced with attribution to the COVID-19 Disability Rights Monitor (COVID-19 DRM). The authors, editors and members of the Coordinating Group of the COVID-19 DRM accept no liability in any form arising from the contents of this publication.

Acknowledgments

The Coordinating Group of the COVID-19 Disability Rights Monitor (DRM) wishes to thank all those who responded to the COVID-19 DRM Survey, the organisations of persons with disabilities and the non-governmental organisations which disseminated the survey.

We especially thank Ms Catalina Devandas Aguilar, former UN Special Rapporteur on the Rights of Persons with Disabilities, Mr Dainius Pūras, former UN Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health and Ms Ikponwosa Ero, UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism for their endorsements of the COVID-19 DRM initiative. We also thank Dr Ciara Siobhan Brennan for leading the analysis of the responses to the survey.

The Coordinating Group of the COVID-19 DRM also wishes to acknowledge the assistance of the following translators of the survey and web developers for their valuable contributions: Jonathan Center (Albanian – Shqip); Cicik Perkasa (Bahasa Indonesia); “Shunte Ki Pao??” Organisation (In English “Can You Hear?”) (Bangla); Aneta Genova, Vladimir Mirchev and Tsvetelina Marinova (Bulgarian); Natasa Kovic (Croatian, French); Ines Bulic Cojocariu (Croatian); Šárka Dušková (Czech, Slovak); Frank Sioen and Tina Sioen (Dutch); Laurence Le Blet, Carlota Gonzalez and Sarah Degée (French);

Laura Partridge (French, German); Petra Flieger (German); Kamil Goungor (Greek); Erzsébet Oláh and Sándor Gurbai (Hungarian); AIFO – Italian Association Amici di Raoul Follereau (Italian); Laura Alčiauskaitė (Lithuanian); Elvin Sciberras from the Commission of the Rights of Persons with Disability – Malta (Maltese); Disability Holistic Development Service Organisation Nepal (DHDSO) (Nepali); Regina Cohen and Mariana Seara (Portuguese); Ion Schidu and Valerian Mamaliga (Romanian); Alyona Khorol (Russian); Nina Portolan and Dragana Ciric Milovanovic (Serbian); Maroš Matiaško (Slovak); Polona Curk (Slovenian); Lisbet Brizuela and Ivonne Millan (Spanish); Girma Gadisa Tufa, Hari Tesfaye Kerga, Nahom Abraham Woldeabzghi and Imad Tune Abdulfetah (Amharic); Mai Mamoun Mubark Aman and Osman Eisa (Arabic); Zoltán Várady and András Váradi (web developers).

The Coordinating Group is thankful to Inclusion Europe for producing an Easy-To-Read version of the Executive Summary of the final report.

Contents

Soundbites	4	Part 4 Significant and fatal breakdown of community supports	28
Acronyms	6	4.1 Breakdown of community supports	28
Executive summary	7	4.2 Access to information	30
The COVID-19 Disability Rights Monitor (COVID-DRM)	8	4.3 Access to food and essentials	31
Overview of the report	9	4.4 Police brutality, harassment, and abuse	32
Conclusions and Recommendations	12	4.5 Recommendations on Community Supports	34
Part 1 Introduction	14	Part 5 Disproportionate impact on underrepresented groups of persons with disabilities	35
Part 2 Methods	16	5.1 Children with disabilities	35
2.1 A human rights-based approach	16	5.2 Women and girls with disabilities	37
2.2 Data analysis	18	5.3 Homeless persons with disabilities	37
2.3 Limitations	18	5.4 Persons with disabilities in remote and rural areas	39
2.4 Responses	19	5.5 Recommendations to Mitigate Impact on Underrepresented Persons with Disabilities	40
2.5 Participants	20	Part 6 Denial of access to healthcare	41
Part 3 Inadequate measures to protect persons with disabilities in institutions	22	6.1 Denial of treatment for COVID-19 and triage discrimination	41
3.1 Failure to protect the lives, health and safety of persons with disabilities in institutions	23	6.2 No access to medication and essential healthcare	42
3.2 Further deprivation of liberty	24	6.3 Recommendations on Inclusive and Comprehensive Access to Healthcare	45
3.3 Measures to inform people in institutions about the state of emergency	25	Part 7 Conclusion	46
3.4 Older persons with disabilities in institutions	26	Endnotes	48
3.5 Recommendations for Governments Related to Persons with Disabilities in Institutions	27	Glossary of terms	50
		Coordinating organisations	54

List of figures

Figure 1	Geographical origins of submissions	19
Figure 2	Respondents by identity	20
Figure 3	Government measures to protect the lives, health, and safety of persons living in institutions	22
Figure 4	Government measures to protect children living in residential schools	23
Figure 5	Social isolation in institutions	24
Figure 6	Measures to inform people in institutions about the state of emergency	26
Figure 7	Measures to protect the lives, health, and safety of older persons in institutions	26
Figure 8	Measures to protect the life, health and safety of persons in the community	28
Figure 9	Access to Information about COVID-19	30
Figure 10	Measures to protect children with disabilities	36
Figure 11	Measures to support families of children with disabilities	36
Figure 12	Measures to protect homeless persons with disabilities	37
Figure 13	Measures to protect persons with disabilities in remote and rural areas	39
Figure 14	Access to treatment for COVID-19	41
Figure 15	Access to essential health services	42
Figure 16	Access to specialised healthcare	43

List of tables

Table 1	Countries with the most responses	20
Table 2	Disability category	21
Table 3	Access to community supports and services	29
Table 4	Access to financial supports	29
Table 5	Access to information	31

Soundbites

"The cost of living has gone up exponentially, but our benefits have not"

A female with disability,
Canada

"Desde nuestra organizacion hemos elaborado una encuesta, en la evidenciamos que un alto porcentaje de familias tienen angustia, estres y una situación económica difícil, sin respuesta a la fecha del Estado"

An organisation of persons with disabilities,
Colombia

"Persons with disabilities will suffer the most because most of their support interventions has been stopped"

An organisation of persons with disabilities,
Tanzania

"Me preocupa el triage"

A female with disabilities,
Mexico

"Nothing has been done with regards to inclusion of people living with albinism"

A male with albinism,
Eswatini

"L'accès aux soins a été supprimé pour les malades chroniques et les personnes ayant des troubles psychosociaux. Les suivis ne sont plus assurés"

An organisation of persons with disabilities,
France

"People in institutions are not receiving adequate assistance or access to medical supplies. Staffing is insufficient and at dangerous levels"

A female with disabilities,
United States

"Én autizmussal élek, szociális munkás vagyok. Nem kaptam megfelelő védőeszközt a munkámhoz..."

A male with disabilities,
Hungary

“সরকার কোভিড ১৯ সম্পর্কে
বিভিন্ন ধরনের পদক্ষেপ গ্রহণ
করলেও প্রতিবন্ধী মানুষের জন্য
স্পষ্ট কোন পদক্ষেপের বাস্তবায়ন
আমরা দেখতে পাইনা।”

A male with disabilities,
Bangladesh

“Ci hanno
abbandonato”

A female with
disabilities, Italy

“The government has supported
virtually everyone else, and
left people with disabilities
to fend for themselves”

A female with disabilities, Australia

“Без рехабилитация,
без разходки, без
специализирана помощ...”

A family member of a person
with disability, Bulgaria

“We have been
forgotten about”

A female with disabilities,
New Zealand

“Mental health services
which are community based
are not available, this put
beneficiaries at risk of relapse”

An organisation of persons with
disabilities, South Africa

“Mehr Arbeitslosigkeit, mehr
Segregation durch (teil)Betreutes
Wohnen: größere psychische
Belastungen ebenda, mehr
Ungleichheit im Bildungsbereich,
weniger Informationen”

A person with disabilities, Austria

Acronyms

Acronym	Stands for
CEDAW	Convention on the Elimination of all Forms of Discrimination Against Women
COVID-19 DRM	COVID-19 Disability Rights Monitor
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DRF/DRAF	Disability Rights Fund/Disability Rights Advocacy Fund
DRI	Disability Rights International
ENIL	European Network on Independent Living
IDA	International Disability Alliance
IDDC	International Disability and Development Consortium
IMM	Independent Monitoring Mechanism
OPCAT	Optional Protocol to the Convention against Torture
OPD/DPO	Organisation of Persons with Disabilities/ Disabled People's Organisation
NHRI	National Human Rights Institution
NPM	National Preventive Mechanism, under the auspices of OPCAT
PPE	Personal protective equipment
SDGs	Sustainable Development Goals
UN	United Nations
WHO	World Health Organization

Executive summary

This report has one central purpose: To raise the alarm globally as to the catastrophic impact of the COVID-19 pandemic on persons with disabilities worldwide and to catalyse urgent action in the weeks and months to come.

The report sets out the outcomes of a rapid human rights-based global monitoring initiative – the COVID-19 Disability Rights Monitor (COVID-DRM) – sponsored by a consortium of seven leading disability rights organisations, which took place between 20 April and 8 August this year. Through centring the testimonies of 2,152 respondents from 134 countries, predominantly from persons with disabilities themselves, the report draws the worrying conclusion that states have overwhelmingly failed to take sufficient measures to protect the rights of persons with disabilities in their responses to the pandemic.

Perhaps most troubling of all, it highlights that some states have actively pursued policies which result in wide-scale violations of the rights to life and health of persons with disabilities, as well as impacting on a wide range of other rights including the rights to liberty; freedom from torture, ill-treatment, exploitation, violence and abuse; the rights to independent living and inclusion in the community, and to inclusive education, among others. Such practices give rise to specific instances of discrimination on the basis of disability, and must be directly challenged and prevented.

Notably, these issues are not confined to developing countries alone. While the pandemic has strained public authorities in virtually every country, one significant finding of this study is

that persons with disabilities report being left behind in countries regardless of their level of development, across both wealthy and developing states. In many cases, the disproportionate impact of the virus and state responses could have been predictable – and steps should have been taken to mitigate some of the worst effects. In some cases, the failure to act has had fatal consequences. In other cases, states have taken actions which cause further harm to persons with disabilities such as through denying access to basic and emergency health care, imposing dangerous lockdowns on overcrowded institutions, and through heavy-handed enforcement of public security measures.

One of the most common faults has been the failure to genuinely include persons with disabilities in the collective response – both at national and global levels. Policymakers at many levels appear to have reverted to treating persons with disabilities as objects of care or control, undermining many of the gains of recent years to enhance citizenship, rights, and inclusion. The testimonies collected throughout the initiative and presented in this report show that this is a faulty approach which runs counter to human rights advancement.

If we are to have any hope of bringing the pandemic under control, it is crucial that states ground their responses in human rights which are genuinely inclusive of all persons with disabilities.

The COVID-19 Disability Rights Monitor (COVID-DRM)

As the novel Coronavirus started spreading around the globe at the beginning of 2020, disability rights organisations quickly began receiving *ad hoc* reports from persons with disabilities that problems were emerging. Worries were expressed about the possible implications of virus transmission in institutions, services to persons with disabilities were being strained, and people were experiencing increased difficulties in accessing general health care. The World Health Organization (WHO) announced that the virus outbreak had become a global pandemic on 11 March, following which unprecedented measures were rapidly adopted by states around the world to install lockdowns and ‘stay at home’ orders. Many undertook emergency measures to reorganise their health care systems, and the majority of states began closing schools, workplaces and large sections of their economies.

In March, the Validity Foundation proposed the creation of an international survey to collect information in real-time regarding the impact of the virus and state measures to respond to the pandemic on the human rights of persons with disabilities. A Coordinating Group was established,¹ formed of the representatives of seven organisations which advocate for the rights of persons with disabilities worldwide, who collectively developed the COVID-19 Disability Rights Monitor (COVID-DRM). A survey was designed to collect information about state measures to protect key rights guaranteed under the United Nations (UN) Convention on the Rights of Disabilities (CRPD). The questions focused on the rights to life, health, independent living, and inclusive education. Additional questions concerned measures taken to protect the rights of particularly marginalised populations of persons with disabilities including children, older persons,

homeless persons, women and girls, as well those of persons with disabilities residing in institutions and in rural or remote settings.

Three versions of the survey were created, each targeting a distinct category of stakeholders:

1. Persons with disabilities, family members and their representative organisations;
2. Government representatives; and
3. Independent human rights authorities including National Human Rights Institutions (NHRIs), National Preventive Mechanisms (NPMs), and Independent Monitoring Mechanisms (IMMs) under Article 33(2) CRPD.

The survey was published in 25 languages on a specially-designed website – www.covid-drm.org – and was further disseminated throughout the Coordinating Group’s international networks. The website provided a summary of anonymised data concerning the numbers of responses received, their geographical distribution, and a selection of quotes throughout the period that the survey remained open. The Coordinating Group also undertook a number of targeted advocacy initiatives and presented preliminary findings at the opening session of the CRPD Committee’s resumed 23rd session which took place virtually on 17 August.

Overview of the report

The report is organised around four themes which emerged during the process of analysing responses received to the survey. These themes are:

1. Inadequate measures to protect persons with disabilities in institutions

2. Significant and fatal breakdown of community supports

3. Disproportionate impact on underrepresented groups of persons with disabilities

4. Denial of access to healthcare

Parts One and Two provide a detailed description of the approach taken in designing and disseminating the survey, including the approach and methods deployed. A human rights-based approach to research was consciously pursued throughout, while a mixed-methods analysis of both qualitative and quantitative data gave rise to four core themes which are explored below. The vast majority of responses came from persons with disabilities and their representative organisations, with the survey receiving over 3,000 separate pieces of written testimony, many of which described serious and life-threatening situations for persons with disabilities in 134 countries.

In contrast, and despite the determined efforts of the partners on the project, very few responses were received from governments and independent human rights authorities. This fact alone underlines one of the core conclusions of this study, namely that governments have yet to adopt truly inclusive responses to the pandemic – a situation which must change if our societies are to build back better. Although the study also sought information from NHRIs and other independent bodies about their efforts to monitor disability rights during the pandemic, very few actually responded to the survey, and those that did explained that their monitoring activities had been severely restricted. This raises concerns about a lack of independent human rights monitoring throughout the pandemic – strengthening the need for the present study.

The following four parts provide detailed analysis of the findings under four themes.

Part Three outlines the shocking situation for persons with disabilities who live in various types of institutions throughout the world, with hundreds of testimonies describing mass fatalities, a lack of preparedness to prevent virus transmission, and shocking accounts about the implications of total lockdowns on residents who were often denied even basic information about how to keep themselves safe.

The findings starkly confirm some of the worst fears of disability rights advocates as to the inherently dangerous nature of congregate settings at any time and point to a reckless disregard of policymakers to take protective measures. Institutionalisation itself is a human rights violation, and while all states which have ratified the CRPD are under an obligation to end this practice and promote independent living, the lack of progress in many countries prior to the pandemic inevitably subjected residents with disabilities to extreme risks.

In a number of countries, respondents pointed out that emergency health care was denied to adults and older persons in institutional settings, amounting to a grave violation of the rights to life and health. The CRPD Committee recently added its authority to this call by establishing a Working Group on Deinstitutionalisation in early September, to guide and push for rapid action by those states which maintain such residential facilities.²

Part Four looks at evidence suggesting a serious breakdown in provision of support for persons with disabilities in community settings, again underlying a lack of preparedness on the part of many states which left people isolated, without access to basic necessities such as food and nutrition, and forced to battle against significant barriers to receiving healthcare, even for those with long-term and chronic health conditions.

In-home services and personal assistance schemes were reportedly halted or severely curtailed in many countries, and while some governments took steps to provide emergency supplies to their populations during lockdowns, a number of respondents with disabilities pointed out that they could not access such schemes.

A large number of respondents raised concerns about the severe impacts of enforced periods of isolation on their mental health, though there were few avenues available to receive practical support, a situation which is likely to have enduring and long-term consequences.

Although there were some positive examples of governments beginning to provide information about the pandemic, this was far from consistent and many respondents reported a distinct lack of accessible information related to the pandemic and how to keep themselves safe. A worrying picture also emerged about the enforcement of curfews and other 'stay at home' orders on persons with disabilities, with numerous reports of violence, harassment, threats, and the imposition of disproportionate fines, as well as a number of tragic fatal incidents. It was reported in a number of countries that the only genuine community-based support was provided by volunteers and civil society organisations, in particular DPOs, with such responses rarely being sponsored by government authorities.

Part Five assesses the situation of underrepresented populations of persons with disabilities, who reported experiencing multiple forms of discrimination and marginalisation, resulting in serious human rights violations. Underrepresented populations include women and girls with disabilities, homeless persons, children, older persons, those living in rural or remote areas, deaf or hard of hearing persons, persons with intellectual disabilities, persons with psychosocial disabilities, persons with deafblindness, and persons with autism.

The majority of respondents reported that their governments had taken little or no action to protect the lives, health, and safety of children with disabilities, with concerns including the lack of provision of personal protective equipment (PPE), the withdrawal of the limited support provided to families, and the near-total exclusion of children with disabilities from education as schools were closed or adopted online teaching environments which were largely inaccessible. Separately, numerous reports suggested a dramatic increase in gender-based violence against women and girls with disabilities including rape, sexual assault, and harassment at the hands of enforcement authorities or family members.

The survey results suggested that few governments had taken action to address the particular vulnerabilities of homeless persons with disabilities. While some governments did provide temporary forms of accommodation, in other cases policymakers opted to pursue misguided approaches such as rounding people up and placing them into group quarantine settings. Particular challenges were also reported in relation to people with disabilities living in rural and remote settings, both through the lack of availability of essential supplies and services, as well as the inability to access information. At a fundamental level, state responses to the pandemic lacked inclusiveness and often enhanced the exclusion already faced by multiply marginalised populations of persons with disabilities.

Part Six raises profound concerns about violations of the right to health for persons with disabilities, with numerous testimonies suggesting states had adopted triage policies or practices which directly or indirectly denied access to treatment on the basis of disability. While states were forced to take emergency measures to prioritise access to healthcare and many experienced unprecedented challenges in responding to the scale of need as the pandemic raged, discriminatory notions concerning disability resulted in life-threatening decisions to restrict or deny basic and emergency healthcare, including for those who had contracted COVID-19. The situation was reportedly compounded in countries without guaranteed universal healthcare, with numerous respondents reporting that the price of medicines and other treatments had soared, and that treatment for chronic and long-term health conditions had been stopped.

Conclusions and Recommendations

A pandemic is, by definition, a public health emergency of international concern which requires collective action and solidarity at all levels. Thus far, the Coronavirus pandemic has had a devastating impact on the rights of persons with disabilities. Recovery efforts will only be effective where they are genuinely inclusive and grounded in human rights. The testimonies collected throughout this study show just how precarious the situation is and that far greater efforts are needed to mitigate the disproportionate impacts of this emergency, including upon those who have traditionally been marginalised on multiple grounds.

As international efforts begin to coalesce around the principle of 'Building Back Better', the Coordinating Group of the COVID-DRM underline the crucial need to include persons with disabilities at all levels of planning and response. We must guard against disempowering notions that persons with disabilities be treated merely as recipients of aid. A sustainable response is possible where leaders with disabilities are acknowledged and become genuine partners in solving problems. The success or otherwise of the international community to tackle the pandemic will ultimately be judged on the extent to which the human rights and dignity of the most marginalised populations are proactively protected and where committed efforts are undertaken to learn lessons to build a better future.

In the rush to respond to the emergency, we must not lose sight of the need to build a sustainable and inclusive recovery process. The Sustainable Development Goals, while adopted far in advance of the pandemic, are more relevant than ever and should guide the collective efforts of public authorities, states, public and private donors as well as regional and international bodies such as the UN. Particular attention should be paid throughout to those at greatest risk of being left behind, including women and girls with disabilities, homeless persons, children, older persons, those living in rural or remote areas, deaf or hard of hearing persons, persons with intellectual disabilities, persons with psychosocial disabilities, persons with deafblindness, and persons with autism. It is also crucial that recovery efforts should not perpetuate pre-existing problems of discrimination and segregated structures of services, such as institutions and residential care for children and adults. Instead, recovery efforts should advance the goals of full rights protection and societal inclusion for all.

While there are many concerns, the report also highlights some promising practices that include persons with disabilities and/or their representative organisations in inclusive COVID-19 responses to the crisis from around the world. In some cases, these were organised and led by organisations of persons with disabilities to respond to clear gaps in state responses. They show that, through working with persons with disabilities, some of the most serious impacts of the pandemic can be mitigated. We urge decision-makers to support such important, community-level initiatives.

The following recommendations should guide immediate action:

1. Ensure that all recovery efforts protect the rights to life, health, liberty, freedom from torture, ill-treatment, exploitation, violence and abuse, the rights to independent living and inclusion in the community, and to inclusive education, among others, for persons with disabilities without any discrimination on the basis of disability.
2. Ensure that all persons with disabilities have immediate access to food, medicine, and other essential supplies.
3. Ensure that persons with disabilities have equal access to basic, general, specialist, and emergency health care and that triage policies never discriminate on the basis of disability or impairment.
4. Enact emergency deinstitutionalisation plans, as informed by persons with disabilities and their representative organisations, including adopting an immediate ban on institutional admissions during and beyond the pandemic, and the transfer of funding from institutions into community supports and services.
5. Allocate adequate financial and human resources to ensure that persons with disabilities are not left behind in the COVID-19 response and in the recovery process.
6. Provide economic, financial, and social support to ensure that persons with disabilities can enjoy their right to fully participate in the community on an equal basis with others, including having access to personal assistance at all times.
7. Guarantee full participation, meaningful involvement, and leadership of persons with disabilities and their representative organisations at every stage of planning and decision-making processes in COVID-19 responses. Take steps to meaningfully involve children and young people with disabilities and their families and caregivers in the design and implementation of all policies in response to the pandemic.
8. Ensure that emergency responses are disability-inclusive and take into account the diverse and individual needs of persons with disabilities, in particular those experiencing intersectional forms of discrimination and marginalisation such as women and girls with disabilities, persons living in rural or remote areas, deaf and hard of hearing persons, persons with deafblindness, persons with intellectual or psychosocial disabilities, and persons with autism.
9. Prioritise inclusive education for children and young people with disabilities, especially children and young people living in congregate care. Ensure alternative education provision is accessible and provides reasonable accommodations based on the individual needs of children and young people with disabilities to guarantee their right to education.
10. Prioritise the dissemination of comprehensive and accessible information in a variety of formats for persons with disabilities concerning the pandemic, response efforts, and public health information and guidance.
11. Provide disability-awareness training for police and law enforcement authorities, and accountability for disproportionate enforcement of public health-related restrictions. Ensure access to justice for persons with disabilities who have experienced or are at risk of experiencing abuse, violence, or exploitation as a result of emergency measures.

Part 1

Introduction

In March 2020, as the COVID-19 virus began to spread, seven organisations focused on the rights of persons with disabilities, namely the Validity Foundation, the European Network on Independent Living, Disability Rights International, the Centre for Human Rights at the University of Pretoria, the International Disability Alliance, the International Disability and Development Consortium, and the sister organisations Disability Rights Fund and Disability Rights Advocacy Fund, joined together to develop the COVID-19 Disability Rights Monitor (DRM). The COVID-19 DRM survey provides an overview of the impact of the global pandemic on persons with disabilities around the world. With data amassed through a major international survey, the DRM was designed as a rapid, emergency monitoring of measures that were taken by governments to protect the rights of persons with disabilities.³

The COVID-19 DRM is committed to amplifying the voices of persons with disabilities, their representative organisations, and their family members as outlined in the findings of the survey to address the human rights violations persons with disabilities are experiencing around the world and ensure COVID-19 responses take into account the diverse and individual needs of persons with disabilities. As responses continue to evolve, it is important that they are rooted in a human rights-based approach proactively adopted by decision-makers, grounded in the human rights protections set out under international law, including the almost-universally adopted Convention on the Rights of Persons with Disabilities.

To date, the COVID-19 DRM has widely disseminated the research findings. Three emergency statements were released while the data analysis was ongoing. The statements called on governments to take immediate action to:

1. end the catastrophic human rights abuses in institutions;⁴
2. end police violence and brutality;⁵ and
3. ensure access to food, medication, and other essential supplies.⁶

An urgent action⁷ was also initiated concerning the situation in residential institutions and calling for persons with disabilities to be immediately provided access to COVID-19 treatment in Romania. The COVID-19 DRM also had an impact at the international human rights level. At the opening of the 23rd session of the UN Committee on the Rights of Persons with Disabilities, on 17 August 2020, the COVID-19 DRM shared the preliminary findings of the global survey.⁸

The questionnaire was available in 25 languages. It remained open for three months, from 20 April until 8 August 2020. During this period, there were 2,152 responses collected from people in 134 countries. The survey received an overwhelming number of responses from persons with disabilities (863), their representative organisations (525), and their family members (448).

Within the questionnaire responses respondents provided more than 3,000 written testimonies documenting the experiences of persons with disabilities and their family members during the pandemic. The qualitative and quantitative data provide in-depth, comprehensive insights into the experiences of persons with disabilities and the consequences of government actions or inactions on the rights of persons with disabilities.

This report presents the findings of the largest internationally comparable dataset, at the time of the publication, on how persons with disabilities worldwide were significantly and negatively affected by the COVID-19 pandemic. The findings reveal that governments around the world have failed to protect the numerous rights of persons with disabilities, namely the rights to life, health, liberty; freedom from torture, ill-treatment, exploitation, violence, and abuse; the rights to independent living and inclusion in the community; and the right to inclusive education. The report presents the findings in four thematic parts:

1. Inadequate measures to protect persons with disabilities in institutions
2. Significant and fatal breakdown of community supports
3. Disproportionate impact on underrepresented groups of persons with disabilities
4. Denial of access to healthcare

The report also highlights some promising practices from around the world that include persons with disabilities and/or their representative organisations in inclusive COVID-19 responses to the crisis. In the absence of inclusive government measures, persons with disabilities and their representative organisations led and advocated for more disability-inclusive responses to the pandemic.

An organisation of persons with disabilities in Belarus said:

“Where DPOs are strong, accessibility is higher than non-DPO locations. DPO leadership is very important, as proven in many areas.”

For decades persons with disabilities and their representative organisations have effectively advocated for and performed crucial developmental and humanitarian functions on every continent and region of the world, often under challenging conditions. The COVID-19 DRM calls on duty-bearers and signatories of the CRPD to remember their commitment to the inclusion of persons with disabilities and their representative organisations in any and all government responses to COVID-19. By definition, there can be no inclusive response to COVID-19 without the involvement of persons with disabilities and their representative organisations. Persons with disabilities and their representative organisations are critical in developing more inclusive COVID-19 responses and must have greater recognition and support from governments as well as decision-making authority.

Part 2

Methods

On April 20, 2020, the COVID-19 DRM launched a global survey to conduct rapid independent monitoring of state measures concerning persons with disabilities in the context of the COVID-19 pandemic. The survey gathered quantitative and qualitative information (i) on the experiences of persons with disabilities, and (ii) on how States are responding to states of emergency situations in relation to this specific population. The survey was designed to use triangulation methodology in order to be able to collect and compare data from different stakeholders:

- from governments
- from national human rights monitoring mechanisms, and
- from persons with disabilities and their representative organisations.

2.1 A human rights-based approach

The COVID-19 DRM survey applied a human rights-based approach to data collection, data analysis, and dissemination of the findings. Participation is central to a human rights-based approach.⁹ The survey was designed to maximise the participation of persons with disabilities and their representative organisations from around the world.

The following tactics were used to garner equal responses from the three main stakeholder groups (persons with disabilities, governments, and national human rights institutes) and collect information:

1. Multiple forms of survey – The questionnaire was available online through the COVID-19 DRM website for respondents who had access to the internet. Print versions of the survey were also provided for those with less reliable access to the internet. When responses to the survey were received in a Word document, a member of the COVID-19 DRM Coordinating Group entered the responses into the online survey and deleted the original Word document in line with the General Data Protection Regulation (GDPR).
2. Availability of survey in over two dozen languages – The survey was available in 25 languages in total, including Albanian, Amharic, Arabic, Bangla, Bulgarian, Croatian, Czech, Dutch, English, French, German, Greek, Hungarian, Indonesia Bahasa, Italian, Lithuanian, Maltese, Nepali, Portuguese, Romanian, Russian, Serbian, Slovak, Slovenian, and Spanish.
3. Support to survey takers and distributors – A web-based dashboard contained guidelines for the dissemination¹⁰ of the survey, which explained the aims and objectives of the study in the same 25 languages listed above, to ensure a consistent understanding of the purpose of the survey and the use of the data collected.

4. Extensive dissemination to the public – The survey was sent out via email, sometimes on a weekly basis, and discussed on webinars with the global and regional networks of each Coordinating Group member. Social media campaigns were also launched via Twitter, Facebook, Instagram, and WhatsApp.
5. Targeted sampling to key stakeholder groups – The members of the Coordinating Group also targeted specific geographical regions, including Asia, Eastern Europe, and Oceania. Examples of targeted outreach include outreach by DRF/DRAF to its grantee networks in 32 countries where its grantmaking is active. ENIL shared the survey among its members in the Council of Europe area, focusing on countries in Western and Southern Europe. They also shared the survey among EU-level networks representing persons with disabilities and others, such as Equinet, which brings together Europe’s equality bodies. ENIL, Validity, and DRI also held a webinar on Emergency Deinstitutionalisation on 11 June 2020 and presented the survey to over 150 attendees.¹¹ Additionally, DRI sent the survey to approximately 70 persons from Mexico and Guatemala, including people with disabilities, mental health users, families, activists, and professionals on the ground, as well as to 13 Mexican government authorities, including local and federal authorities, the National Human Rights Commission, the Ministry of Health, the Federal Psychiatric Care Services, the National System for the Integral Development of the Family, and the Undersecretary of Prevention and Health Promotion from the Ministry of Health. Validity also undertook direct targeting of key stakeholders in Hungary, Romania, the Republic of Moldova and Russia, including through sharing the survey with national organisations of persons with disabilities and state authorities, as well as following up individually by phone and email.

6. Accompaniment of human rights advocates to potential survey respondents – Graduate students at the Centre for Human Rights at the University of Pretoria administered the survey to individual respondents.

The data was disaggregated by key characteristics identified in international human rights law. The survey contained closed and open-ended questions that aimed to gather data about what States are doing to protect the core rights of persons with disabilities. These core rights included the right to life, the right to access healthcare, the right to live independently in the community, and the right to access services. To disaggregate the data, questions requested personal data, such as sex, country of residence, and disability category. However, respondents had the options to both withhold personal information and to remain anonymous.

Transparency was another key rights-based consideration when collecting data for the DRM survey. The survey findings were made publicly available on the COVID-19 DRM website. The website contains a dashboard that provides information about the number of responses from each country, selected, anonymous quotes¹² from respondents from around the world, and a weekly summary of the findings¹³. The identities of all respondents are protected. All identifying details have been removed from the data before it was published. In addition, all data collected was stored and managed in line with the General Data Protection Regulation (GDPR).

2.2 Data analysis

Mixed-methods data analysis was used to analyse the data through an inductive research approach.¹⁴ The survey contained open-ended and closed questions. The combination of qualitative and quantitative data provided a nuanced, in-depth insight into the experiences of persons with disabilities, and state measures to protect the rights of persons with disabilities during the pandemic. The quantitative data was analysed in Microsoft Excel. In addition to responding to the quantitative questions, most participants chose to provide several written testimonies in the open-ended questions. The survey received more than 3,000 written testimonies. They varied in length from a short sentence to long paragraphs. Prior to content analysis, testimonies in one of the 24 non-English languages listed above were translated into English using Google Translate. The testimonies were coded and thematically analysed. The key themes that emerged were: access to healthcare, access to food and essential supplies, conditions in institutions, and access to community support and services. These themes are discussed in detail in the findings section. The qualitative data was used to explore the meaning of the quantitative data in more detail. The qualitative data captured the voices of the respondents to the study.

2.3 Limitations

The survey was designed as a rapid response to an emergency situation that arose from the COVID-19 pandemic. The methodology utilised was appropriate and proportionate to the objectives of the COVID-19 DRM. However, there were several limitations that arose as a result of the quick turnaround of the survey design. Firstly, the survey was available neither in an easy-to-read format nor any sign language. Secondly, the survey was available online through the Disability Rights Monitor website, which limited the responses to persons who have online access. Thirdly, the responses were not equally representative of various regions

of the world. Despite efforts to translate the survey and dissemination guidance into different languages, there was a low response rate from Arabic-speaking countries and Russian-speaking countries. Response rates were low in many Asian countries as well, but this may have been a result of the unavailability of the survey in major Asian languages. Efforts to mitigate these limitations included the availability of a print version of the survey, additional outreach by the Coordinating Group members to their respective networks, webinars with government officials and national human rights institutes, and an extension of the survey closing deadline by three weeks.

Fourthly, unequal response rates from the three stakeholder groups – persons with disabilities, governments, and national human rights institutes – were also a limitation. The survey was initially intended to triangulate the data from the three stakeholder groups. However, this was not possible given the low response rates from governments and human rights monitoring mechanisms. Instead, online research and third-party documentation were the main methods of data verification. This included documentation through media accounts, national human rights or ombudsman reports, or networks of organisations of persons with disabilities.

Fifthly, given the specialised nature of the topics covered in the questionnaire, respondents had the option to select “not my area of expertise” as a response to the closed-ended questions. These responses were treated as missing data and were excluded from the data analysis. While this is a limitation, it allowed the survey to cover a wide range of specialised topics. The final figures in the findings section only include those in which respondents chose another option.

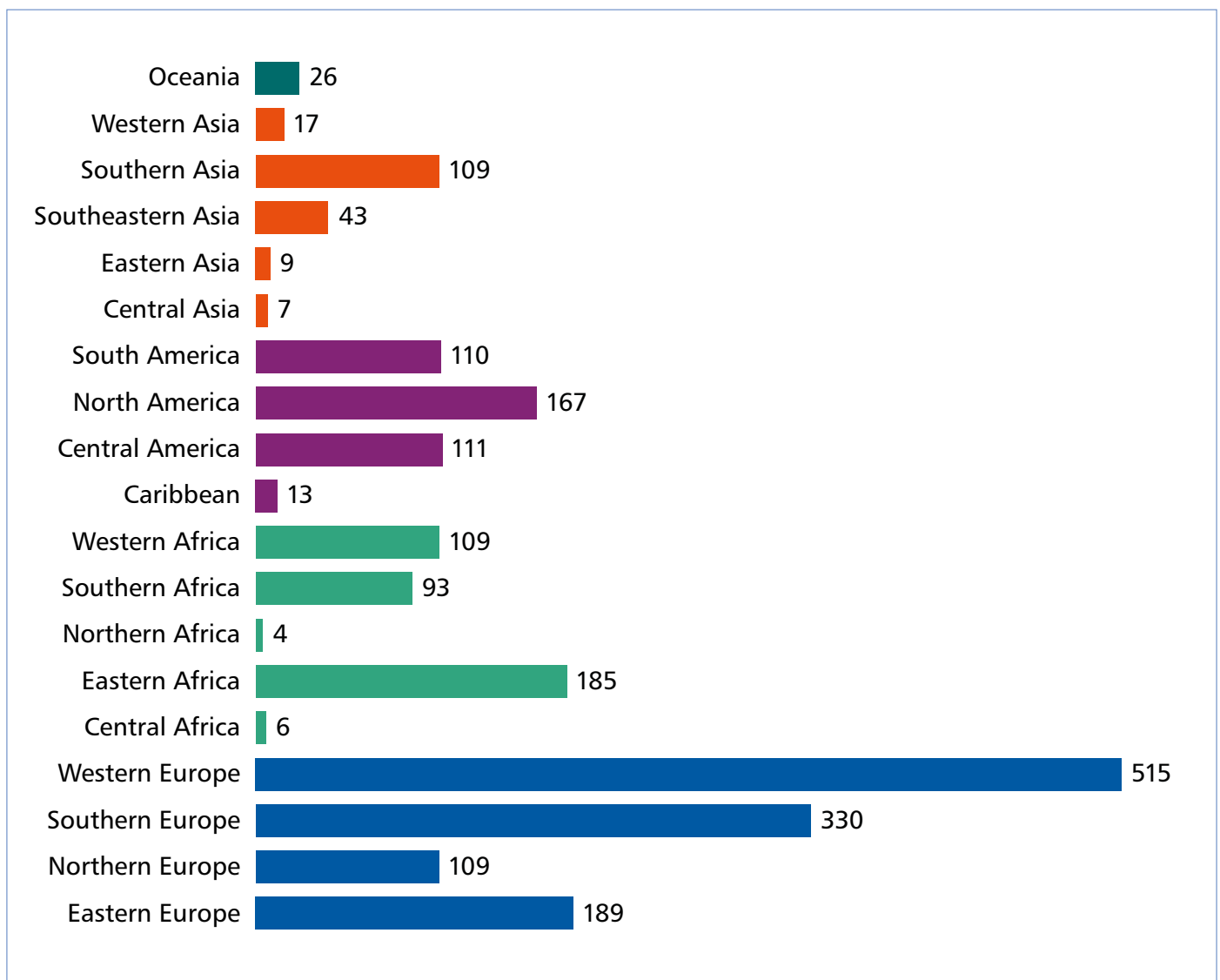
Lastly, several of the open-ended questions were removed from the survey while it was still active. The decision to remove these open-ended questions was made to reduce the length of the survey.

2.4 Responses

The survey received 2,152 responses from 134 countries between April 20, and August 8, 2020. Despite the best efforts of the COVID-19 DRM to disseminate the survey among governments and human rights institutions, the survey received a very low number of responses from these stakeholders (26 governments and 12 human rights institutions). However, the survey received an overwhelming number of responses (2,112)

from persons with disabilities, their representative organisations, and family members, making it the largest internationally comparable dataset on the experiences of persons with disabilities during the COVID-19 pandemic.

Figure 1 Geographical origins of submissions



The countries with the highest number of responses, listed below in Table 1, were Germany (225), Italy (130), and France (130). The United States was the North American country with the highest number of responses (94). South Africa was the African country with the highest number of responses (83). Mexico had the highest responses (73) from Central and South America. India had the highest number of respondents (50) in Asia.

Table 1 Countries with the most responses

Ranking	Country	Number of responses
1	Germany	225
2	Italy	130
3	France	130
4	Austria	105
5	United States	94
6	South Africa	83
7	Mexico	73
8	Canada	63
9	Nigeria	62
10	Slovenia	52

2.5 Participants

The majority of respondents (1,325) identified as female, 695 identified as male, and 92 identified as others or did not disclose. Most respondents, as shown in Figure 2, were persons with disabilities (863), the next largest group of respondents were organisations of persons with disabilities (525), followed by family members (448), and others (276). The other category included NGOs, persons working in services for persons with disabilities, and persons working in institutions for persons with disabilities.

The respondents represented a diverse range of constituencies. The largest constituency was persons with physical disabilities (943), followed by women with disabilities (540), and persons with intellectual disability (524), as outlined in Table 2.

Figure 2 Respondents by identity

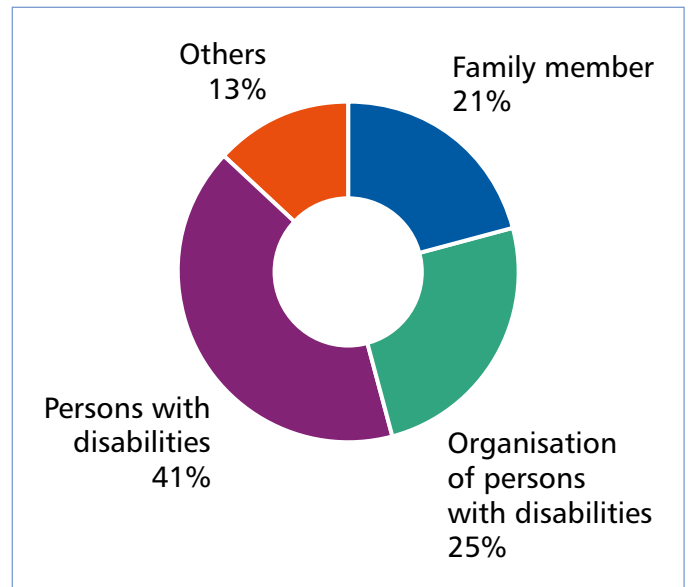


Table 2 Disability category

Which disability category do you identify with or represent/advocate for?	Number
Physical disability	943
Women with disabilities	540
Intellectual disability	524
Carer	448
Psychosocial disability	447
Deaf	418
Autism	403
Blind	388
Down's Syndrome	351
Hearing	348
Deafblind	161
Indigenous	115

Part 3

Inadequate measures to protect persons with disabilities in institutions

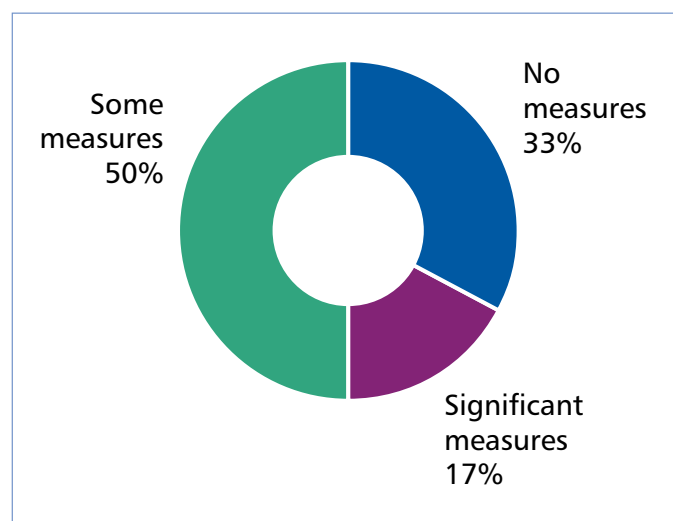
The findings of the COVID-19 DRM survey suggest that governments around the world have failed to protect the right to life of persons with disabilities in institutions during the pandemic. While the institutionalisation of persons with disabilities is in itself a violation of human rights, the 329 written testimonies from 50 countries demonstrate how the emergency measures that were taken by governments to control the spread of COVID-19 have exacerbated existing human rights abuses and failed to prevent further human rights abuses. These measures included the denial of access to healthcare, bans on visitors, and isolating residents when there was an outbreak of COVID-19.

The highest number of these testimonies came from high-income countries including Germany, Austria, France, and Canada. They reveal grave and systemic violations of fundamental freedoms and human rights of persons with disabilities detained in large- and small-scale institutions, which have become the epicentre of COVID-19 infections and deaths. These institutions include group homes, psychiatric hospitals, retirement homes for older persons with disabilities, residential schools for children, and other residential settings where persons with disabilities are detained against their will. Congregate living arrangements within institutions are inherently

more dangerous as infectious diseases can quickly spread without proper and swift precautions. Thirty-three percent of respondents said that governments took no measures to protect the lives, health, and safety of persons with disabilities living in institutions, as shown in Figure 3 below.

The rapid spread of COVID-19 within institutions was foreseeable, and states should have taken steps to protect the right to life for persons with disabilities.

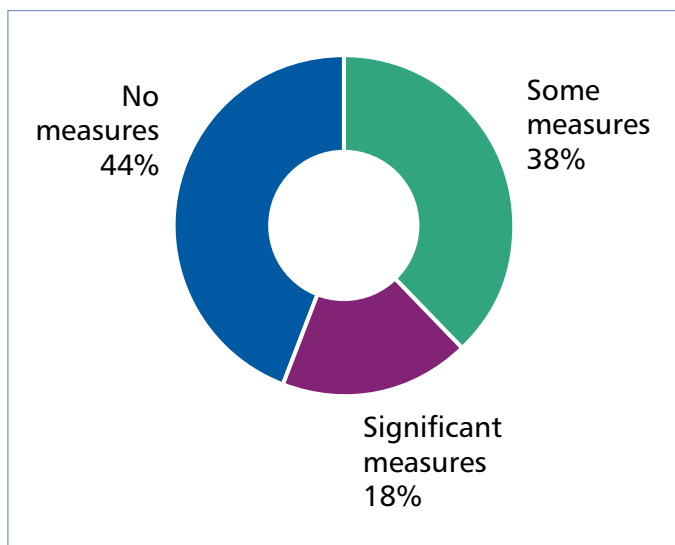
Figure 3 Government measures to protect the lives, health, and safety of persons living in institutions



3.1 Failure to protect the lives, health and safety of persons with disabilities in institutions

The survey findings shed light on the deadly conditions that resulted in the high death rates within large-scale and small-scale institutions. As shown in Figure 4 below, of those who answered, 44% (486) of respondents said that their government took no measures to protect children with disabilities in residential schools. Thirty-three percent (476) of the respondents who knew about the situation in institutions said that their government took no measures to protect the lives, health, and safety of persons with disabilities in institutions.

Figure 4 Government measures to protect children living in residential schools



The written testimonies provide a shocking insight into the situation of persons with disabilities in institutions. The survey received an overwhelming number of testimonies from around the world confirming that governments have not taken sufficient steps to safeguard the right to access food, basic medical supplies, personal protective equipment, or measures (such as social distancing) to minimise infections and deaths in institutions. A respondent with disabilities described the conditions inside the

Herron residence in Quebec: The other residents were malnourished, dehydrated, and severely neglected. The institution was “dangerously understaffed. There were people dead in their beds, others laying on the floor and some others with three layers of diapers and dehydrated.”

The survey received more than 60 written testimonies that governments failed to provide personal protective equipment (PPE) and adequate sanitation in institutions. The countries with the most written testimonies about the lack of PPE and cleanliness in institutions were the USA, the UK, Canada, Ireland, and South Africa. Written testimonies from people who were inside the institutions confirmed that there was a lack of access to PPE. For instance, a staff member from a Moldovan institution said that they had to buy their own PPE, without reimbursement from either the institution or the government.

There were also complaints of understaffing in institutions and of inadequately trained staff. Moreover, respondents complained that staff was transferred from one institution to another, allowing for the further spread of infection. There were complaints from around the world that governments did not act quickly enough to prevent COVID-19 outbreaks in institutions, and when measures were taken, it was already too late. Furthermore, if measures were taken, they were usually initiated by the institution, not the government. As a result, some respondents feared that the institutions had too much autonomy to decide the fate of the residents.

**Promising example:
provision of PPE in Palestine**

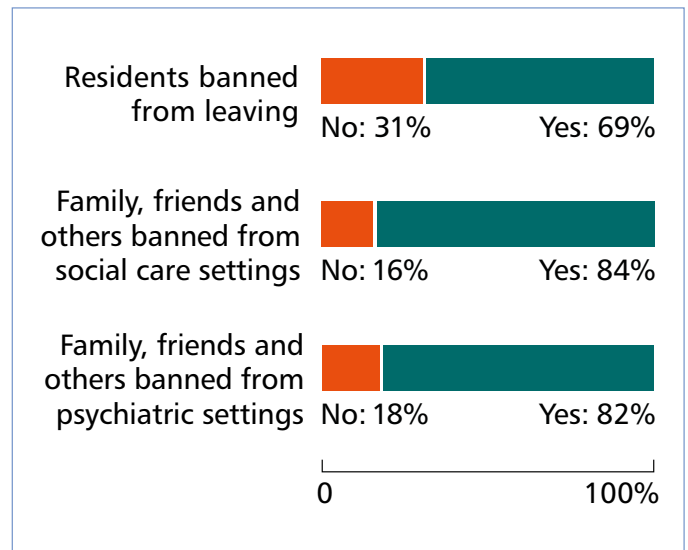


There were also examples of DPOs, NGOs, and UN agencies providing PPE and hand sanitisation in institutions. For instance, a Palestinian respondent said that PPE was not provided “directly by the government, but by International Organisations, such as UNICEF and some national NGOs.” There was a joint strategy of the humanitarian community, including UN agencies, and NGOs, and the Palestinian government to respond to immediate humanitarian consequences of the pandemic.¹⁵

3.2 Further deprivation of liberty

While institutions have always deprived residents of their liberty, the COVID-19 pandemic has made the situation even worse. Institutions around the world were cut off from the rest of society, without any monitoring mechanisms in place. Of the measures that were taken by governments, some of these included a ban on visitors and a ban on residents leaving. Of those who knew about the situation, the majority, 69% (819), said that persons with disabilities were restricted or banned from leaving the institutions (refer to Figure 5 on the right). A further 84% (1,172) said that the government had banned, or restricted visits from family, friends or others in social care settings, and 82% (984) of those who knew about the situation in psychiatric health facilities said that their government had banned visits.

Figure 5 Social isolation in institutions



Family members of persons with disabilities and organisations of persons with disabilities expressed grave concerns for their family members’ safety and wellbeing within institutions. While institutions were closed to prevent the spread of infection, there were fears that additional human rights abuses would occur behind closed doors, in the absence of monitoring mechanisms or family visits to institutions. A Bulgarian organisation of persons with disabilities feared that the measures that were taken to “prevent infection, but it is also a measure that could lead to a lack of care, lack of transparency and concealment of dangerous abuses.” This sentiment was echoed around the world. In Guatemala, there were concerns for the three-hundred persons with disabilities who were sealed into the Federico Mora psychiatric facility without social distancing or access to hospital care.

Authorities have denied access to independent human rights authorities to monitor the health and safety of detainees.¹⁶ A Greek organisation of persons with disabilities described the psychiatric institutions as “hermetically sealed with more absolute restrictions than before, with no possibility of visits, with no advocacy services and with no independent monitoring.”

Respondents were particularly concerned about the mental health of the residents. For instance, a German respondent feared that “the measures may help to prevent infection from COVID-19. But the psychosocial impact on people with disabilities cannot be underestimated.”

Respondents also feared for the mental health of children with disabilities in institutions.

A person with disabilities in Belgium said:

“From what I know, children in institutions are strictly confined, can no longer have contact with their families. They are really imprisoned while the providers bring the virus. Very significant mental consequences.”

The survey received written testimonies from staff and medics who had been inside institutions. These testimonies confirmed the fears of family members and organisations of persons with disabilities. Respondents who had been inside institutions during the pandemic reported that residents were overmedicated, sedated, or locked up. This situation is having a devastating effect on the mental health of the residents. An organisation of persons with disabilities from Andorra reported that “self-harm has occurred and the solution by the institution has been overmedication.”

Promising example: Twenty-four hour helpline in Moldova



A Moldovan organisation for persons with disabilities provides a 24/7 complaints mechanism helpline for persons with disabilities living in Moldovan institutions. Mobile phones were provided for self-advocates in institutions for calls in case of rights violations.¹⁷

3.3 Measures to inform people in institutions about the state of emergency

There were reports that people living in institutions did not receive information about the pandemic and the emergency measures that were put in place by their governments. For instance, 26% (322) of respondents said that no measures were taken to inform persons with disabilities living in institutions about the state of emergency, including the bans and restrictions on visitors (refer to Figure 6 overleaf for additional responses). Many respondents were worried that persons with disabilities in institutions were cut off from society, without any knowledge of the state of emergency. They were concerned that persons living in institutions were not provided with adequate information to protect themselves from COVID-19.

An organisation of persons with disabilities in India said:

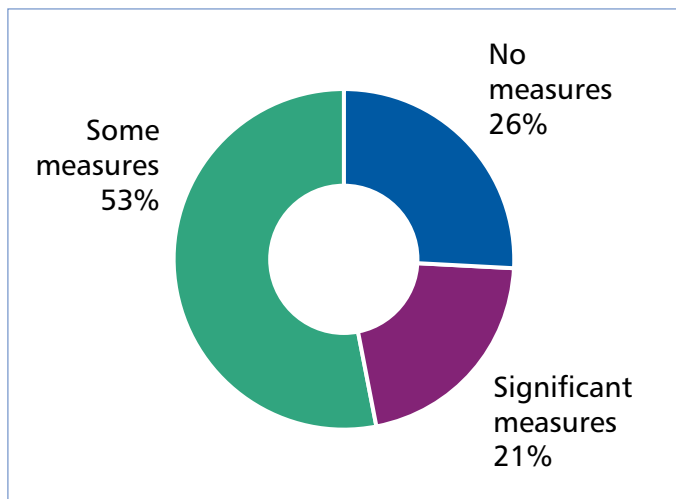
“A few things have been put up online at relevant government portals but most persons with disabilities have no access to these staying in institutions. Perhaps they don’t even know what is going on outside!!”

Promising example: Easy-to-read material made available in Serbia¹⁸



With the support of UNICEF, Mental Disability Rights Initiative of Serbia produced an Easy-to-read material which was distributed to people with disabilities in residential institutions and in the community.

Figure 6 Measures to inform people in institutions about the state of emergency



3.4 Older persons with disabilities in institutions

One-third (506) of the respondents who knew about the situation said that their government took no measures to protect the life, health, and safety of older persons (refer to Figure 7 on the right for additional responses). Of those who said that some measures were taken, many went on to explain that these measures were problematic, including bans on visits from family members, friends, and human rights monitors. Respondents were concerned for the effects that the isolation was having on the mental health of older persons in institutions.

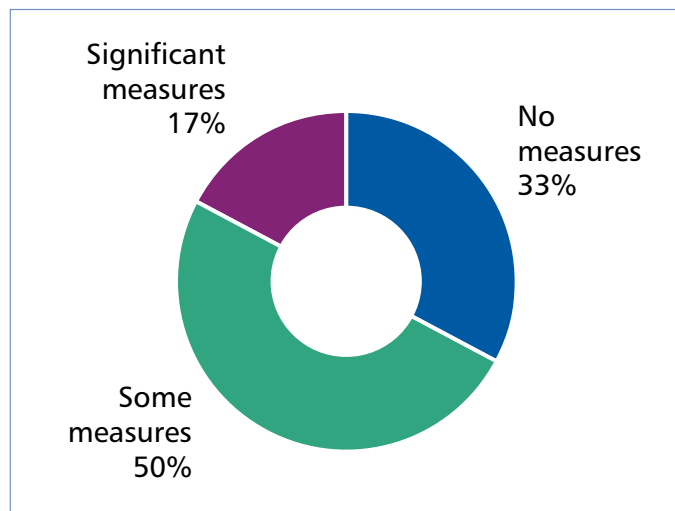
A person with disabilities in Italy said:

“Many people didn’t even have an explanation as to why they couldn’t see their families anymore. Many older people thought they were abandoned and left to die.”

Testimonies criticised governments for not acting quickly enough to protect older persons in residential settings from the spread of the virus. For instance, an Irish respondent with disabilities said that “the measures taken to protect persons in institutions was a bit late coming, almost an afterthought.” Respondents also complained

that their governments took general measures that did not ensure the protection and inclusion of older persons with disabilities. A Haitian organisation of persons with disabilities explained that “no specific measures have been taken in favour of older persons with disabilities.”

Figure 7 Measures to protect the lives, health, and safety of older persons in institutions



Promising example: Sanitisation efforts in Sudan



There were several promising examples, where governments prioritised the health and safety of older persons with disabilities in institutions. Such measures included access to PPE, social distancing, as well as frequent testing for COVID-19.

The Sudanese government was praised for their efforts to sanitise residential homes for older persons with disabilities. Sudanese “NGOs, in collaboration with government agencies, conducted awareness-raising sessions, about COVID-19 and how to stay safe, distributed hand sanitizers, and conducted sanitisation rounds of institutions for older persons with disability.”

3.5 Recommendations for Governments Related to Persons with Disabilities in Institutions

In accordance with their obligations under international law, particularly the UN Convention on the Rights of Persons with Disabilities (CRPD), the COVID-19 DRM calls on governments, funders, and global actors to take the following emergency response to avoid further catastrophe:

1. Develop an emergency deinstitutionalisation plan in line with Article 19 of the CRPD and General Comment No. 5: Right to independent living (2017) of the CRPD Committee.¹⁹
2. Implement an immediate no-admissions policy to large- and small-scale institutions.
3. Closely monitor the situation in institutions and release data and information on the number of infections and fatalities in institutions.
4. Guarantee immediate, unfettered access to independent national human rights authorities, including NHRIs and NPMs, to all institutions, ensuring safety protocols and procedures are in place to enable independent monitoring and direct communication between monitors and residents.
5. Provide immediate access to food, PPE, social distancing measures, and appropriately trained staff.
6. Provide accessible information in multiple formats about the state of emergency.
7. Ensure full access to healthcare on an equal basis with other citizens.
8. Implement immediate measures to ensure that residents can contact law enforcement and complaints mechanisms, and to ensure contact with family and friends.
9. Ensure that persons within institutions have access to mental health supports and services.
10. Prevent family separation and institutionalisation of children (or parents) due to COVID-19 pandemic.

The DRM also calls on governments to take the following longer-term steps to avoid future human rights emergencies:

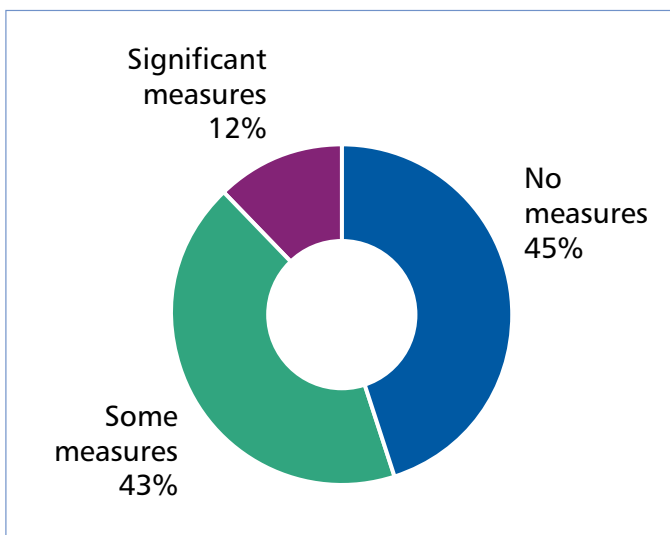
11. Actively involve persons with disabilities and their representative organisations, and civil society, in planning the recovery process and emergency deinstitutionalisation plans.
12. Allocate adequate financial and human resources to support the transition from institutions to the community, in line with Article 19 of the CRPD.

Part 4

Significant and fatal breakdown of community supports

Forty-five percent (777) of participants said that their government took no measures to protect the life, health, and safety of persons with disabilities living in the community (refer to Figure 8 below for additional responses). Many persons with disabilities living in the community said that they were abandoned by the government and trapped at home, with no means to access food, medicine, or other basic supplies. Respondents from countries with particularly strict curfews were at increased risk of police harassment, intimidation, and violence.

Figure 8 Measures to protect the life, health and safety of persons in the community



4.1 Breakdown of community supports

Many of the essential services that persons with disabilities rely on to live independently in the community were not available during the pandemic. For example, as outlined in Table 3 below, 38% (809) of the survey respondents said that persons with disabilities did not have access to personal assistance. Thirty-three percent (708) said that persons with disabilities did not have access to informal care. A further 23% (490) said that persons with disabilities did not have access to assistive technologies.

A very small minority of respondents reported any financial assistance from their governments during the pandemic, as outlined in Table 4 below. Only 6.5% (138) of respondents reported that their governments provided cash as a social protection measure to support persons with disabilities, only 10% (205) said that persons with disabilities received financial support, and only 12% (258) said that persons with disabilities had access to benefits.

Respondents said that persons with disabilities were living in isolation, with no community supports. A large number of respondents expressed grave concerns about the effects of isolation on the mental health of persons with disabilities.

Table 3 Access to community supports and services

Services and supports that persons with disabilities cannot access during the COVID-19 pandemic	Percentage	Number of respondents
No access to personal assistance	38%	809
No access to informal care	33%	708
No access to home support	29%	604
No access to assistive technology	23%	490

Table 4 Access to financial supports

Government measures to financially support persons with disabilities living in the community	Percentage	Number of respondents
Benefits	12%	258
Financial support	10%	205
Cash	6.5%	138

A representative of an organisation of persons with disabilities in Uganda said:

“Due to isolation and social restrictions it has caused a lot of fear and psychological pain, anxiety, with uncertainty about what will happen next. This may culminate into an increase in mental breakdowns and increase in suicide cases.”

Persons with disabilities around the world reported that they lost their independence during the COVID-19 pandemic. Some persons with disabilities said that they were forced to rely on their family members, charities, or NGOs for survival. An Italian respondent with disabilities said “I am afraid that my mum will die of exhaustion and then I will die without her assistance.”

Promising example: collaborative emergency response in Indonesia

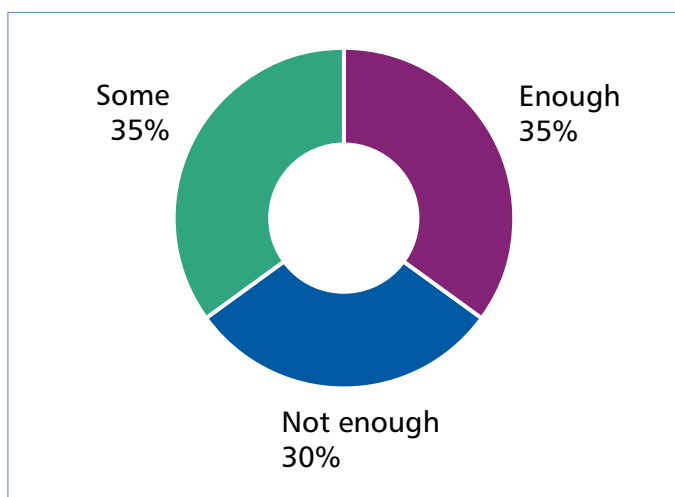


Several testimonies described a collaborative emergency response by Indonesian organisations of persons with disabilities. Online meetings were held to discuss the situation of persons with disabilities living in the community led by the Indonesian Mental Health Association. Collective action plans were developed, including the development of videos²⁰ to raise awareness of the mental health implications of isolation.²¹

4.2 Access to information

Almost one-third (621, 30%) of respondents said that persons with disabilities did not receive enough information about the prevention of COVID-19 (refer to Figure 9 below for additional responses). The COVID-19 DRM received 345 written testimonies about access to information during the pandemic. There were concerns about access to information in hospital facilities and when persons with disabilities living in the community were isolated without any contacts.

Figure 9 Access to Information about COVID-19



When information about COVID-19 was provided, it was often unclear and confusing. Respondents from Australia, the USA, the UK, and Colombia complained that their government spread misinformation or confusing information about the state of emergency. For instance, an Australian respondent with disabilities complained of “inconsistency & confusion in information on social distancing and use of PPE.” Similarly, a Colombian respondent with disabilities was concerned about the “confusing access to all the information that is provided daily.”

The majority of respondents with disabilities accessed information about the pandemic on television, radio, or social media. However, there were concerns that persons with disabilities living without access to these technologies did not have adequate information about the pandemic. Respondents from Ethiopia, Malawi, Lesotho, Rwanda, and Zimbabwe said that there was no access to information for persons with disabilities living in remote and rural areas.

A representative of an organisation of persons with disabilities in Lesotho said:

“No measures have been taken to inform persons with disabilities about the virus especially in areas where such individuals can’t access information through radio or television.”

When asked if information about COVID-19 was available in accessible formats, 21% of respondents said that information was not available in any accessible formats. Sign language was the most widely-available accessible format (44%), followed by easy-to-read (38%) and audio (33%), as outlined in Table 5 below. Concerns were also raised about the lack of specific types of information, including preventive measures to prevent infection, where to obtain testing and treatment, the nature of emergency regulations and lockdown rules, and accessing emergency food and social assistance schemes.

Table 5 Access to information

Information available in Accessible Format	Percentage	Number
Sign Language	44%	938
Easy-to-read	38%	798
Audio	33%	693
Multiple languages	23%	490
Screen readers	22%	461
Not been provided	21%	448

Promising example:
Sign language videos in Rwanda 

In March 2020, the Rwanda National Union of the Deaf (RNUD) in partnership with local government authorities and the Office of the Prime Minister released one of many sign language videos. A Rwandan respondent said that “interpretations during the TV COVID prevention campaigns have enhanced access to information. The Deaf organization increased its efforts by translating all the inaccessible information and sharing them via all social media platforms in a very accessible format (sign language and simplified video).”²²

4.3 Access to food and essentials

The survey has revealed that persons with disabilities around the globe did not have access to food and adequate nutrition during the COVID-19 pandemic. Almost one third (633) of the survey respondents in 81 countries said that persons with disabilities in their country could not access food. The ten countries where the highest percentage of respondents reported no access to food were Uganda, Nigeria, Kenya, Bangladesh, India, Colombia, Côte d’Ivoire, Tanzania, Rwanda, and Peru. Several high-income countries were

also among those with high proportions of people who said that they could not access food. More than 25% of respondents from Belgium, Canada, France, the United States of America, and the United Kingdom said that persons with disabilities did not have access to food during the pandemic. The findings indicate that the vast majority of governments did not take the appropriate steps to safeguard and promote the right to access food.

The survey received 131 written testimonies about access to food and adequate nutrition. The written testimonies provide a deep insight into the nature of food distribution across the world. There were reports of increased prices, loss of income, and inadequate financial support during the pandemic. Several respondents from high-income countries complained that they could not afford food and basic necessities as a result of the rising cost of living, including a rise in the cost of medication and rent.

In many countries, persons with disabilities were living in poverty before the COVID-19 pandemic. Respondents described how the measures taken by their governments created even worse situations for persons who relied on begging or low-paid jobs to buy food.

A representative of an organisation of persons with disabilities in Nepal said:

“The government announced the stay at home order and lockdown, but could not think of poor daily wage earners who are not getting even a meal a day. People are deprived of food and are in financial crisis and the government has not provided any benefits.”

Many respondents from high-income countries felt that they were abandoned in their homes, with no way of access to food. The COVID-19 DRM survey received written testimonies from persons with disabilities in Australia, Belgium, Canada, France, Switzerland, the United States of America, and the United Kingdom who said that they could not access food during the pandemic. Eight respondents from the United Kingdom complained that persons with disabilities were not included on the government’s list of groups that were vulnerable to food shortages. Other barriers identified by respondents included the harsh enforcement of lockdown orders by police and security officials, the removal or severe restriction of necessary personal assistance, and allegations that public food distribution schemes were either inaccessible or unavailable to persons with disabilities, particularly those without relevant documentation.

When food was available, the distribution was initiated by NGOs, organisations of persons with disabilities, or charities, and not by the government. Although some people were receiving food packages, these were planned at the local, rather than the national, level, leading to uneven food distribution throughout the country and food relief efforts not reaching persons with disabilities living in remote and rural areas. Available food packages were often insufficient and did not take special dietary requirements into account. Some people relied on food packages from charities and NGOs.

There was also evidence that people relied on informal supports, such as family, friends, or neighbours to access food.

Promising example: Helpline for older persons in Malta



In Malta the Ministry of Social Policy created a helpline for older and vulnerable people to provide them with support regarding food and medicines that were coordinated and delivered to their homes. There was also a specific email address established for the Deaf community to request food and medicine.

4.4 Police brutality, harassment, and abuse

Around the world persons with disabilities and their family members have had no choice but to break curfew rules to access food and essential medical supplies, because no exceptions were made for them. Public information campaigns were largely inaccessible throughout the pandemic. The majority of respondents (77%, 1105) said that they did not have information about penalties resulting from breaking state of emergency rules (fines, sanctions, arrest) imposed on persons with disabilities. Furthermore, one-third of respondents said that they did not have access to food or medical supplies. This resulted in a dangerous situation in which police and security forces tasked with enforcing lockdowns encounter persons with disabilities leaving their homes to meet their basic needs.

The COVID-19 Disability Rights Monitor survey received 370 written testimonies from all continents. The testimonies reveal an alarming global phenomenon of police harassment, torture, and murder of persons with disabilities and their family members. The findings indicate that persons with disabilities were particularly vulnerable to various forms of exploitation, violence, and abuse in countries with strict curfews and strong police or military presence. In the most extreme cases, breaking curfew rules was a matter of life or death. For example, an Army veteran²³ with post-traumatic stress disorder was shot and killed in the Philippines. A respondent from a Ugandan organisation of persons with disabilities said “I know two PWDs who have been shot at because they were outside in curfew time. These were deaf people and didn’t know what was happening.”

There were reports of police brutality against women and girls with disabilities who broke the curfew rules to seek food. For instance, a respondent from a Nigerian organisation of persons with disabilities said that “a mother of a child with Cerebral Palsy was harassed by policemen on her way to collect food relief at one of the distribution centres.” Likewise, a Ugandan respondent said that “a woman with a disability was beaten up after curfew time. She was looking for food.” A South African respondent said that “parents have been fined or arrested for going to buy diapers or medication for their child with a disability.”

Respondents from around the world reported that they were living in fear of the police. In Europe, respondents from Italy, the UK, and France said that they were afraid to leave their homes. Many people believed that the police were unreasonable and heavy-handed.

An Italian respondent said that “fines were given to persons with disabilities who sat on benches or went out on the street with their caregivers.” A Russian respondent with disabilities said that they were “caught by police on the street. They took my personal data and warned me that next time I would be charged a fine for the same offense.” Emergency measures enacted by the French government to allow persons with autism to go out more often were criticised by three participants. They condemned the law for giving the French police powers to determine who is autistic. A French respondent explained that there were “fines for persons with autism or parents of children with autism who have permission to go out but the police find ‘not autistic enough’.”

There were also stories of police harassment of family members trying to make contact with their loved ones, many of whom were locked inside institutions, with no means of contacting the outside world. A French respondent said that “a lady was fined for waving (hello) out the window (closed) to her husband who lives in a retirement home.” A Norwegian organisation of persons with disabilities said that “families/legal guardians trying to visit have sometimes been threatened with police action.”

4.5 Recommendations on Community Supports

In accordance with their obligations under international law, particularly the UN Convention on the Rights of Persons with Disabilities (CRPD), the COVID-19 DRM calls on governments, funders, and global actors to take the following immediate steps to avoid a further breakdown of community services and supports:

1. Guarantee full participation and meaningful involvement of persons with disabilities and their representative organisations at every stage of the response.
2. Safeguard community-based services including personal assistance, home supports, and assistive technology.
3. Provide information about the state of emergency in multiple, accessible formats.
4. Enact emergency measures to ensure adequate and affordable food and medication distribution throughout the country, including rural and remote areas.
5. Provide immediate financial assistance to persons with disabilities to cover the additional cost of living and the rise in the cost of food, medications, and other essential supplies.
6. Work with private sector companies such as supermarkets to ensure that food is delivered to the homes of persons with disabilities who are unable to leave, and encourage them to allocate dedicated times for vulnerable shoppers, including persons with disabilities.
7. Investigate and hold accountable police and other security services which abuse, injure, or kill persons with disabilities.
8. Put in place necessary measures to protect persons with disabilities who are in situations of risk, especially during curfews, lockdowns, shielding orders, or shelter at home orders related to the COVID-19 pandemic.
9. Ensure all security briefings and reports take into consideration the perspectives and rights of persons with disabilities during the COVID-19 pandemic.
10. Ensure police officers and security forces are trained to take into account the specific needs of persons with disabilities during the COVID-19 pandemic.

Part 5

Disproportionate impact on underrepresented groups of persons with disabilities

Specific populations of particularly marginalised persons with disabilities have been disproportionately affected by the COVID-19 pandemic. Governments around the world have failed to recognise the impact of the pandemic on groups that are multiply marginalised. They have failed to take measures to include and protect the most underrepresented groups of persons with disabilities, including children, women and girls, persons experiencing homelessness, and persons living in remote and rural locations.

The partners on the COVID-19 DRM initiative sought to gain information on the specific situation facing children with disabilities, older persons with disabilities, homeless persons with disabilities, and those living in rural and remote locations. However, responses also captured the experiences of other underrepresented populations including women and girls with disabilities, deaf or hard of hearing persons, persons with intellectual disabilities, persons with psychosocial disabilities, persons with deafblindness, persons with autism, and persons with disabilities from indigenous communities. Inclusive responses must not only respond to the specific issues faced by these populations, but should proceed on an intersectional basis, addressing the enhanced risks faced by persons

with disabilities who experience multiple and intersecting forms of discrimination.

5.1 Children with disabilities

The survey findings suggest that children with disabilities were disproportionately affected by the measures taken by governments during the pandemic and experience multiple forms of discrimination on the basis of disability and age. Forty-three percent (623) of respondents who knew about the situation of children said that their government took no measures to protect the health and safety of children with disabilities in institutions or in the community. The written testimonies reveal that many essential supplies and services were unavailable to children in the community and in institutions. Respondents from around the world reported that children did not have access to food and medicine. Moreover, children with disabilities did not have access to essential healthcare, respite care, rehabilitation, or education.

The majority (55%, 867) of the survey respondents said that their government had taken no measures to support families of children with disabilities during the pandemic. In most cases, governments did not take disability-specific measures and did not take child-specific measures. For instance, a respondent from the

UK said that “children were not included in any of the definitions of ‘vulnerable’ to COVID 19 – only adults.” Hence, children with disabilities are in a situation of compounded vulnerability.

Figure 10 Measures to protect children with disabilities

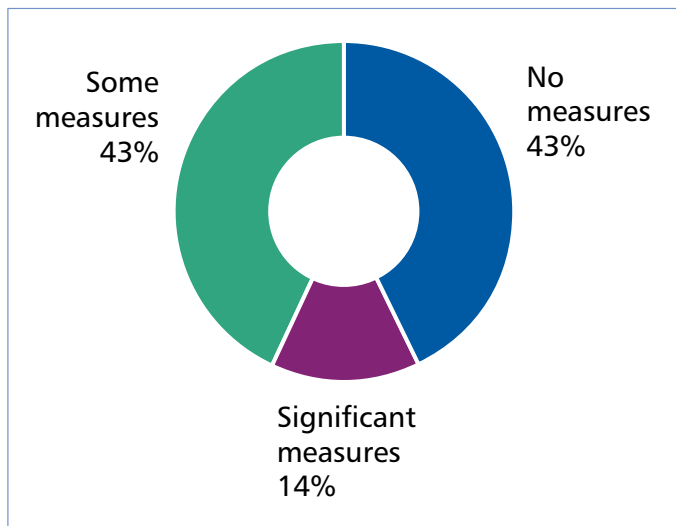
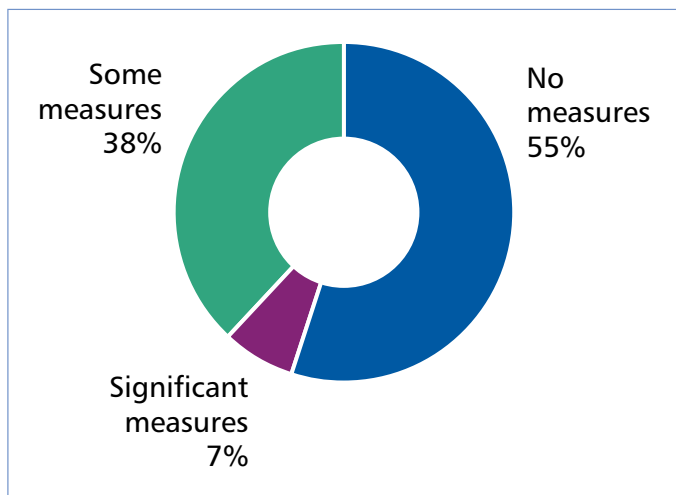


Figure 11 Measures to support families of children with disabilities



Children living in poverty and children living in rural or remote areas relied on NGOs and charities to deliver essential supplies such as food and medication. However, there were reports that NGOs could not deliver essential, potentially life-saving supplies to children with disabilities. Furthermore, there were reports that children who relied on schools or disability services for food and medication could not access them during the pandemic.

A representative of an organisation of persons with disabilities in Kenya said:

“It’s the [disability] organisations that are trying to help children in this pandemic. The government has even refused some of our organisation to help and deliver the medical care the people with disabilities may need in their communities.”

Children with disabilities around the world did not have access to education and other essential services. The survey received reports that children with disabilities were excluded from remote schooling. For instance, respondents from Malawi and Moldova described how children with disabilities were excluded from remote learning because they did not have access to technology.

A representative of an organisation of persons with disabilities in Malawi said:

“Many school-going children with disabilities have not been considered in the newly introduced school radio program and are left out in these school radio programs.”

Families who were instructed to stay at home with their child with a disability reported that they did not receive any guidance or financial support from the government. For instance, an Irish family member explained that “families of those children are relying heavily on charities to support them and each other. We have literally been left to fend for ourselves.”

5.2 Women and girls with disabilities

The survey findings suggest that women and girls with disabilities have been disproportionately affected by the COVID-19 pandemic and experience specific rights violations due to the interaction of discrimination on the basis of disability and gender identity, as well as age. The survey received 25 testimonies of grave human rights abuses which included multiple forms of assault and violence. There were reports of sexual assault, domestic violence, and police brutality against women and girls with disabilities.

Respondents feared that the actions taken by governments, which made women and girls with disabilities more isolated than ever before, would increase the risk of sexual violence. The respondents were extremely critical of the absence of government interventions and support for women and girls who had experienced sexual assault.

A representative of an organisation of persons with disabilities in Nepal said:

“Recently, a girl child aged 10 years who lives with intellectual disability has been raped. Hence the government should take measures.”

A person with disabilities in Czechia said:

“I am an abuse survivor, and I cannot access services for survivors. No one cares about medical trauma connected to sexual abuse.”

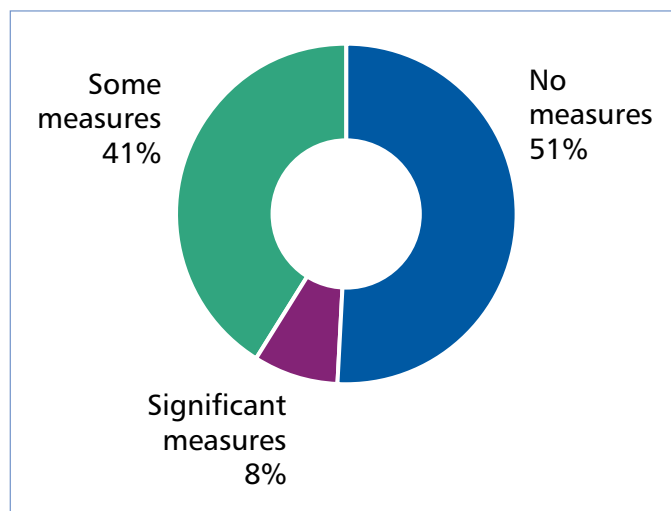
Respondents from around the world complained that their governments did not take measures to safeguard the rights of women and girls with disabilities. While the respondents acknowledged that violence against women and girls with disabilities has always been a problem, the pandemic has made the situations even worse because women and girls could not access police, women’s shelters, social workers, or trauma

counselling during the pandemic and were isolated at home with abusive partners or relatives and with no access to school or workplaces.

5.3 Homeless persons with disabilities

Fifty-one percent of respondents (667) who were aware of the situation of homeless persons with disabilities said that their government took no measures to protect the life, health, and safety of persons with disabilities living on the streets or in homeless shelters, as outlined in Figure 12 below.

Figure 12 Measures to protect homeless persons with disabilities



The survey received 74 written testimonies about homeless persons with disabilities, who experience discrimination on the basis of age and socio-economic status. Many respondents were extremely concerned about their health and safety, especially children with disabilities living on the streets. The findings suggest that persons with disabilities were at an increased risk of homelessness as a result of the pandemic.

A representative of an organisation of persons with disabilities in Nepal said:

“Recently, a woman with a disability had to face food shortage and did not have any house/shelter. She was denied entry to her own village. She had to live outside of a hospital for a week.”

Respondents from Uganda, Nigeria, Tanzania, and India reported that their governments took inadequate measures to protect children with disabilities living on the streets.

A representative of an organisation of persons with disabilities in Nigeria said:

“Children (with disabilities) and their parents are still in the street with no face masks, no social distancing. Their lives are in danger.”

The COVID-19 DRM survey has received disturbing testimonies that homeless persons with disabilities were detained against their will and moved to institutional settings that were inaccessible and unsafe. In Uganda, an organisation of persons with disabilities raised specific concerns about street children who are allegedly being “quarantined in some boarding school facilities.” A Rwandan respondent with disabilities said that “wanderers with psychosocial disability... have been removed to a psychiatric facility to keep them inside by force. They are provided with minimal assistance.” There were also reports of persons with disabilities being rounded up by the authorities and sent to institutions. There were particular concerns about the mental health of persons with psycho-social disabilities who were detained in institutions.

A representative of an organisation of persons with disabilities in India said:

“Irrespective of disabilities, persons on streets are picked up and put into shelters. These provide basic survival supports to all people housed there. This has great implications for persons with psychosocial disabilities, who have been experiencing homelessness but free and living at will on streets – to be institutionalized.”

There were also reports that persons with disabilities became homeless when their families could not care for them. A Kenyan organisation of persons with disabilities reported that “persons with intellectual disabilities have been neglected by their families with the nurses (at a psychiatric hospital) recording 15 cases last month being admitted as they were now homeless.”

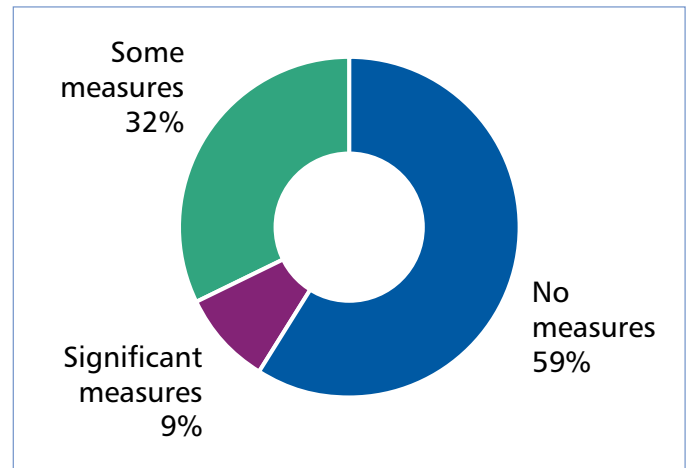
There were concerns for the health and safety of homeless persons with disabilities who were provided with temporary accommodation. For instance, respondents were concerned that temporary accommodation did not offer the opportunity to social distance or protect oneself from contracting COVID-19. A Canadian respondent complained that “homeless shelters that are not enforcing social distancing and COVID-19 cases have been detected within the homeless community.” Likewise, a Ugandan respondent was concerned that “street children and homeless persons were taken in an institution, but the challenge is the idea of social distancing.”

There were a few promising reports of governments supporting homeless persons with disabilities to return to their homes. For instance, a Tanzanian organisation of persons with disabilities said that “the government has supported to register and identify persons with disabilities living in the streets and taken them back to the home villages.” However, the organisation went on to warn that “the challenge of how to monitor the progress and support them in their homesteads has not sufficiently resolved.” While there were reports of governments providing shelter for homeless persons with disabilities in Canada, the UK, the United States, and India, there were similar concerns about the long-term strategy for housing and ensuring community integration of homeless persons with disabilities and ensuring that homeless shelters do not turn into institutional settings providing long-term placements.

5.4 Persons with disabilities in remote and rural areas

The majority of respondents (59%, 792) said that no measures were taken by their government to protect persons with disabilities in remote and rural areas. The survey findings reveal that persons with disabilities in remote and rural areas faced additional barriers to accessing food, medication, and health care. Furthermore, there were concerns that they did not have adequate access to information in areas without access to the internet, phones, and other technologies.

Figure 13 Measures to protect persons with disabilities in remote and rural areas



5.5 Recommendations to Mitigate Impact on Underrepresented Persons with Disabilities

In accordance with their obligations under international law, particularly the UN Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Rights of the Child, and the Declaration on the Elimination of Violence against Women, the COVID-19 DRM calls on governments to take the following measures to safeguard the rights of underrepresented groups of persons with disabilities:

1. Guarantee full participation and meaningful involvement of underrepresented persons with disabilities and their representative organisations in decision and policy-making processes. These include women and girls, homeless persons, children, and those living in rural and remote areas.
2. Ensure that legislation and policies are disability-sensitive and recognise diversity among persons with disabilities and the intersectionality of rights.
3. Closely monitor the situation of underrepresented groups of persons with disabilities and collect data and information on their needs.
4. Ensure that implementation of legislation and policies, especially emergency response, is sensitive to the specific, overlapping needs of persons with disabilities.
5. Provide access to justice, women's shelters, social workers, trauma counselling, and other supports for survivors of domestic violence and sexual abuse.
6. Ensure that children with disabilities have equal access to healthcare, education, food and medicine, and other community services on an equal basis with all children.
7. Guarantee that essential services, such as healthcare and mental health services, are age-appropriate and gender-sensitive.
8. Provide accessible, community-based accommodation for homeless persons with disabilities.
9. Guarantee long-term housing and community integration support services for homeless persons with disabilities.
10. Establish a coordination mechanism within the government to ensure equal access to support services throughout the country, including remote and rural areas.

Part 6

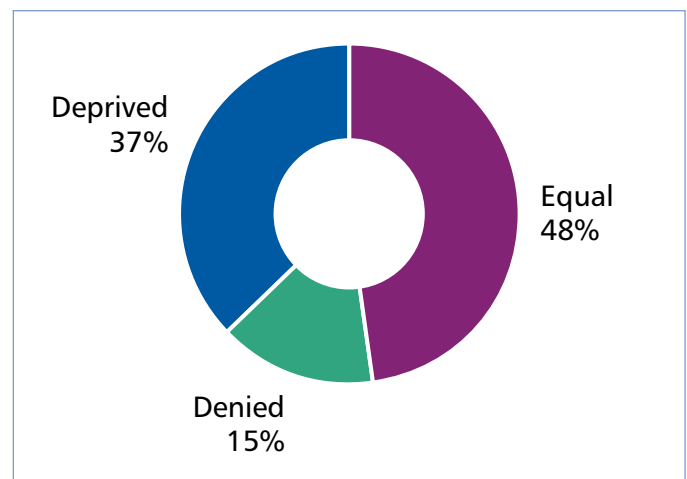
Denial of access to healthcare

The findings of the COVID-19 survey suggest that persons with disabilities were denied access to healthcare on an equal basis with other citizens. The survey received more than 550 written testimonies from around the world regarding access to healthcare. These testimonies provide further insights into the disproportionate denial of healthcare for adults and children with disabilities. Persons with disabilities faced physical, financial, and attitudinal barriers to accessing healthcare on an equal basis with other citizens. These included discrimination in triage, unaffordable medication, and inability to leave home to access essential healthcare and medication. The COVID-19 DRM survey also received alarming testimonies that persons with disabilities were denied or deprived of life-saving treatment for COVID-19 on the basis of disability, resulting in many preventable deaths. These are discriminatory decisions which give rise to grave human rights violations.

6.1 Denial of treatment for COVID-19 and triage discrimination

The majority of respondents who knew about access to healthcare for COVID-19 (52%, 390) said that they were denied or deprived of healthcare for COVID-19 during the pandemic.

Figure 14 Access to treatment for COVID-19



The written testimonies describe discrimination against adults and children with disabilities when trying to access treatment for COVID-19. For example, the survey received a testimony about a Canadian child with autism who was denied a test for COVID-19 “because the attending physician deemed him too difficult to assess. He had all the symptoms of Covid-19 but was refused confirmation.”

Many respondents complained that persons with disabilities living in institutions did not receive adequate medical treatment for COVID-19. In some cases, hospitals refused to treat persons with disabilities.

A representative of an organisation of persons with disabilities in the United Kingdom said:

“A eugenics programme has been undertaken covertly... Do Not Resuscitate Notices (DNRs) were placed on people with no consultation, especially older persons and persons with learning disabilities.”

Several written testimonies from Canada, the United Kingdom, the United States of America, Austria, Luxembourg, the Netherlands, Georgia, France, and South Africa said that their governments indicated that hospital triage should discriminate against COVID-19 patients with disabilities in the event of a shortage of hospital places. Triage guidelines explicitly or implicitly instructed health workers to decide on a person’s right to life based on their disability.

A representative of an organisation of persons with disabilities in France said:

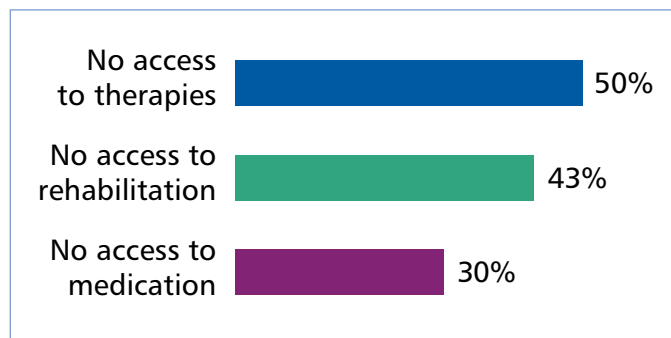
“The SAMU (Urgent Medical Aid Service) and the care services in the event of infection with covid19 have explicitly said to no longer come to institutions. Hospitals have issued recommendations for triage of patients, which said to leave them in an institution.”

6.2 No access to medication and essential healthcare

Persons with disabilities did not have access to essential healthcare during the pandemic. Of those who answered, half (958) of the respondents said that people in their country could not access therapies. A further 43% (918) said that people in their country did not have access to rehabilitation.

Almost one-third (30%, 641) of respondents said that they did not have access to medication during the pandemic. This included essential, life-saving medications, and medication used in the treatment of psychosocial disabilities.

Figure 15 Access to essential health services



Persons with disabilities and their family members encountered multiple barriers to accessing medication. These barriers included unaffordable medications, no transportation, inability to leave home due to curfews, and loss of personal assistance services. Many persons with disabilities said that they could not afford medication. Respondents from high-, middle- and low-income countries reported remarkably similar barriers to accessing essentials. In some cases, lack of access was linked to inflation or the rising cost of living during the pandemic. Others reported that they had difficulty accessing medications before the pandemic.

A person with disabilities in Zimbabwe said:

“To get medicine is not easy in my community, pharmacies demands United States Dollars which the majority don’t have and the medicines are very expensive beyond the reach of many persons with disabilities.”

Respondents from high-income countries such as Canada, the United States of America, the United Kingdom, France, and Australia complained that a rise in the cost of living combined with a breakdown of social and financial support due to the COVID-19 pandemic means that persons with disabilities cannot afford essentials.

A person with disabilities in Australia said:

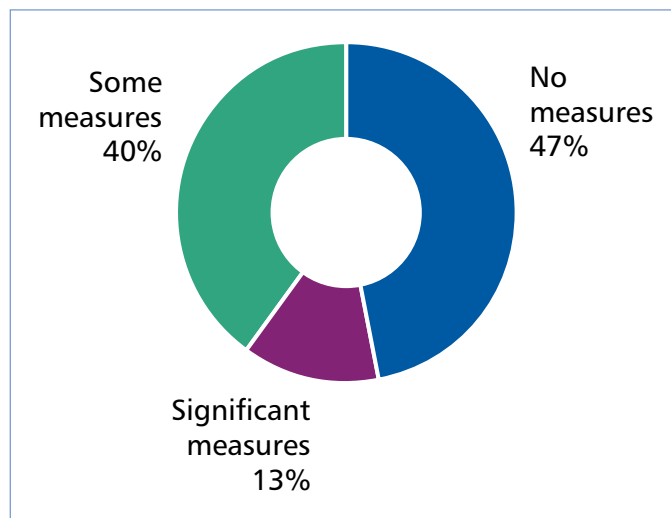
“My main concern is that the living expenses of all people with disabilities have gone up, and continue to go up, and the Australian government insists that they haven’t. Many of us are getting to the point of missing meals altogether, choosing between food, or medication.”

Many people could not access healthcare and medicine because they were trapped at home. Reasons for this included a lack of accessible transport, living in remote, rural areas, and loss of personal assistance services during the pandemic. For example, a respondent with a disability from South Africa explained that “accessible transport is almost non-existing especially from rural areas to hospitals and clinics. A shortage of medication is the norm.”

Governments across the globe failed to ensure that persons with disabilities had access to basic medical supplies, rehabilitation, and therapies. There were a few reports that charities or NGOs were distributing essential medical supplies. For example, an Indian organisation of persons with disabilities was providing community-based rehabilitation for children with disabilities who were sent home from residential schools or from institutions due to the pandemic.

Forty-seven percent (799) of respondents who answered said that their government had taken no measures to ensure that persons with disabilities can access specialised medical care, including pain relief and treatment for psychosocial disabilities.

Figure 16 Access to specialised healthcare



Survey responses also indicate that access to healthcare was restricted in high-, middle-, and low-income countries.

A person with disabilities in South Africa said:

“Conditions like mine need continual care and medical expertise... I can’t see my pain specialist, and he can’t operate on me, because he works out a hospital that isn’t allowing visitors.”

A family member from Norway said that “general and specialised healthcare has been restricted to reduce the spread of the virus, resulting in many people not receiving rehabilitation at all or being waitlisted or treated in places that do not specialize in this.”

Some respondents were concerned that persons with disabilities did not have access to information when they are hospitalised. For instance, an organisation of persons with disabilities from Hong Kong said that “the official sign language interpreters assigned REFUSED to show up at the hospital in this crisis.”

A person with disabilities in Colombia said:

“The very low level of accessibility to health services, which do not have the corresponding reasonable adjustments, and in the case of Deaf people, they have not been able to provide the sign language interpreting service either virtual or in person.”

Respondents reported experiencing high levels of fear and anxiety, including that they might not be able to access medical treatment, that they would be denied treatment for COVID-19 on the basis of disability, concerns that the virus would have a more serious effect upon them in interaction with underlying health conditions, and that they would be deprioritised in decisions about healthcare rationing. In addition, some respondents were concerned about losing access to health and medical services they received prior to the pandemic, and fears were also expressed concerning whether health professionals were adequately trained to administer tests and treatments to persons with intellectual and psychosocial disabilities. A further issue was that the pandemic and restrictive measures imposed by states would have serious mental health consequences.

Promising examples in providing community-based healthcare



There were a few promising examples of healthcare services that were moved from a hospital to a community setting. For instance, a respondent from a Kenyan organisation of persons with disabilities said that because of the high infection rates in the community, psychiatric nurses would visit people in their homes in the community.

Bulgarian respondents highlighted several examples of measures that were taken by the combined efforts of the government, NGOs, and UN agencies to provide health and mental health support during the pandemic. Several Bulgarian respondents said that they could access a helpline for mental health support during the pandemic.

Furthermore, local governments offered support for persons with disabilities to purchase medicine.

6.3 Recommendations on Inclusive and Comprehensive Access to Healthcare

In line with their obligations under the UN Convention on the Rights of Persons with Disabilities (CRPD), the COVID-19 DRM calls on States to take the following measures to protect the right to healthcare on an equal basis with other citizens.

1. Guarantee full participation and meaningful involvement of persons with disabilities and their representative organisations at every stage of health policy making.
2. Prevent denial of health information, health care, or health services on the basis of disability. Provide access to justice for those who have been denied access to healthcare.
3. Ensure that persons with disabilities, including persons living in institutions, enjoy the highest attainable standard of health without discrimination on the basis of disability.
4. Require health professionals to provide healthcare and health information to persons with disabilities on an equal basis with other citizens, including persons in institutions.
5. Raise awareness of disability rights among health professionals, including the right to access information and give free and informed consent to medical treatment.
6. Ensure access to specialised health services including rehabilitation.
7. Guarantee free or affordable healthcare, food and medicine, and prohibit discrimination against persons with disabilities in the provision of health insurance
8. Provide health information and services as close as possible to people's own communities, including in remote and rural areas.
9. Ensure that health information and services are age- and gender-sensitive.
10. Provide information about healthcare in multiple, accessible formats.

Part 7

Conclusion

The unprecedented response to the COVID-19 DRM survey by persons with disabilities, their representative organisations, and families from across the globe has shown the importance of listening to those most affected by the pandemic.

It is these voices, which came through so powerfully in the survey, and these people that have been ignored by governments all over the world. As a result, the emergency response has not been tailored to the specific needs and rights of persons with disabilities, especially those in institutions and belonging to underrepresented groups. This has had dire consequences, resulting in thousands of avoidable and preventable deaths and other serious human rights abuses.

Survey respondents made it clear that during the pandemic, the only support for persons with disabilities in many situations were DPOs and community-led initiatives distributing food and PPE, helping with access to medication and essential supplies, and providing mental health support. While this report has highlighted some examples, it cannot do justice to the crucial work undertaken by many organisations to make up for governments' failings. If there is a lesson to be learned, it is that persons with disabilities and their organisations are key to the planning, preparation and implementation of any emergency response, and their crucial role must be adequately acknowledged and supported and they must be integrated into further response.

Although COVID-19 DRM was designed as a rapid response survey, capturing the impact of the virus on persons with disabilities at a time when it began spreading throughout Europe and the rest of the world, we must remember that we are still in the midst of the pandemic. This is why the statement of former UN Special Rapporteur on the Rights of Persons with Disabilities Catalina Devandas from April 2020 still rings true:

“The COVID-19 pandemic represents a threat to the lives of people with disabilities. COVID-19 is hitting hard in our community, feeding on and deepening the historical and structural discrimination against people with disabilities.

Social care institutions, nursing homes and psychiatric facilities, where people with disabilities are often institutionalised or detained against their will, have become hotspots of the pandemic, accounting for half of the fatalities in some countries. Governments across the world must act fast to guarantee that all COVID-19 responses are accessible and disability-inclusive.”

Members of the COVID-19 Coordinating Group – the Validity Foundation, the European Network on Independent Living, Disability Rights International, the Centre for Human Rights at the University of Pretoria, the International Disability Alliance, the International Disability and Development Consortium and the Disability Rights Fund/Disability Rights Advocacy Fund – wish to see this report’s findings and recommendations used to inform an accessible and disability-inclusive COVID-19 response, now and moving forward, in our shared goal to advance human rights. While emergency actions are required now, we urge all stakeholders to ensure their efforts are built on a sustainable basis, in line with Agenda 2030.

We cannot afford to leave anyone behind if we hope to build back better.

Endnotes

1. For more information about the Coordinating Group members, refer to www.covid-drm.org/group ↗
2. Office of the High Commissioner for Human Rights. Press Release: *Committee on the Rights of Persons with Disabilities Closes twenty-third virtual session*. 4 September 2020, available at <https://bit.ly/34OpRlR> ↗
3. For more information on monitoring the rights of persons with disabilities refer to the document: *Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors (Professional Training Series, No. 17)*, Geneva, United Nations, 2010, available at <https://bit.ly/2lmbWvY> ↗
4. To read the full COVID-19 Disability Rights Monitor (DRM) statement calling for an emergency response to the catastrophic abuse of the human rights of persons with disabilities in institutions, refer to www.covid-drm.org/en/statements/emergency-response ↗
5. To read the full COVID-19 Disability Rights Monitor (DRM) statement calling for an end to police violence and abuse against persons with disabilities and their family members, refer to <https://bit.ly/3dyMyP4> ↗
6. To read the full COVID-19 DRM statement calling on governments to ensure access to food, medication and essential supplies for persons with disabilities, refer to <https://bit.ly/2Td05CJ> ↗
7. To read about COVID-19 DRM urgent action, calling for persons with disabilities to be immediately provided access to COVID-19 treatment in Romania, refer to <https://bit.ly/3lWXrNH> ↗
8. For more information about COVID-19 DRM preliminary findings, presented at the opening of the 23rd session of the UN Committee on the Rights of Persons with Disabilities on 17 August 2020, refer to <https://bit.ly/3duqYv8> ↗
9. For a detailed description of the human rights based approach described here, see: <https://www.ohchr.org/Documents/Issues/HRIndicators/GuidanceNoteonApproachtoData.pdf> ↗
10. To read COVID-19 DRM guidelines for the dissemination of the survey, refer to www.covid-drm.org/guidance ↗
11. A recording of the webinar is available here: <https://bit.ly/2FkqFpU> ↗
12. To access anonymous quotes from respondents from around the world on COVID-19 DRM website, refer to www.covid-drm.org/voices ↗
13. To access weekly summary of the findings on COVID-19 DRM website, refer to www.covid-drm.org/weekly-reports ↗
14. Bryman A. *Integrating quantitative and qualitative research: how is it done?* *Qualitative Research*. 2006;6:97–113. doi: 10.1177/1468794106058877

15. For more information, refer to the COVID-19 Response Plan for the occupied Palestinian territory <https://bit.ly/3jR3KSI> ↗
16. For more information about the situation in Guatemalan mental health hospital during the pandemic, refer to <https://bit.ly/30Z6O7p> ↗
17. For a detailed description of the situation in Moldova, refer to a report by Keystone services <https://bit.ly/3jT8MgS> ↗
18. This example was provided by COVID-19 DRM Coordinating Group member DRI through their local office in Serbia and not collected through the COVID-19 DRM survey.
19. For a detailed legal analysis of deinstitutionalisation, see Office of the United Nations High Commissioner for Human Rights, 2012 *Getting a Life – Living Independently and Being Included in the Community* <https://bit.ly/30XLQpg> ↗
20. To access a video about institutionalised persons with psychosocial disabilities in Indonesia, refer to <https://bit.ly/3lWhl63> ↗
21. This example of a more inclusive COVID-19 response was provided by COVID-19 DRM Coordinating Group member DRF/DRAF and not collected through the COVID-19 DRM survey. Through DRF/DRAF's resourcing of DPOs, a number of DPOs were able to pivot existing advocacy grants to focus on COVID-19 inclusive responses. DPOs have been able to contribute to more inclusive COVID-19 responses at the national and local level.
22. This example of a more inclusive COVID-19 response was provided by COVID-19 DRM Coordinating Group member DRF/DRAF and not collected through the COVID-19 DRM survey. Through DRF/DRAF's resourcing of DPOs, a number of DPOs were able to pivot existing advocacy grants to focus on COVID-19 inclusive responses. DPOs have been able to contribute to more inclusive COVID-19 responses at the national and local level.
23. For more information about mental health implications of isolation, refer to <https://bit.ly/3nYCNi0> ↗

Glossary of terms

Persons with disabilities

As per the definition of the Convention on the Rights of Persons with Disabilities, persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Organisations of persons with disabilities (OPDs/DPOs)

Organisations of persons with disabilities are representative organisations or groups of persons with disabilities, where persons with disabilities constitute a majority of the persons operating at all levels of the organisation, including (as applicable) staff, board, and volunteers.

Disability-inclusive response

To be disability-inclusive, responses to the COVID-19 pandemic must be characterised by a human-rights based approach in line with the Convention on the Rights of Persons with Disabilities and the 2030 Agenda for Sustainable Development. Leaving no one behind is the founding principle of disability-inclusive responses. In practice, State authorities and any other relevant stakeholders must ensure the full participation and meaningful involvement of persons with disabilities and their representative organisations at every stage of planning, decision-making, implementing and monitoring processes in COVID-19 responses. Disability-inclusive response must take into account the diverse and individual needs of persons with disabilities and any related information shall be accessible to persons with disabilities.

Accessibility of information

To be fully accessible to persons with disabilities, information should be published and shared in accessible formats, including by sharing accessible materials online for persons using screen reader software, using universal design elemental and additional formats, such as the use of sign languages, Easy Read, plain language, captioned media, Braille, augmentative and alternative communication, and other accessible means.

Institutions

An institution can be defined as any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise, control over their lives and their day-to-day decisions.

General Comment No. 5 to the CRPD underlines the following defining elements that constitute an institutionalised setting: obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment.

For the purposes of the COVID-19 DRM survey, the concept of ‘institutions’ included the following state and private-run settings: social care institutions, group homes, children’s institutions, boarding schools, psychiatric health care institutions, forensic psychiatric settings, homes for older persons, nursing homes, and shelters for homeless people.

For a child, an institution should be defined as any publicly or privately managed and staffed collective living arrangement that is not family based. Institutions include orphanages, children’s institutions, group homes, infant homes, children’s villages, and residential settings for children.

Deinstitutionalisation

Deinstitutionalisation is a political and a social process which provides for the shift from institutional care and other isolating and segregating settings to independent living. Effective deinstitutionalisation occurs when a person placed in an institution is given the opportunity to become a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of deinstitutionalisation is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. Deinstitutionalisation is also about preventing institutionalisation in the future; ensuring that children are able to grow up with their families and alongside neighbours and friends in the community, instead of being segregated in institutional care.

Community-Based Services (CBS)

The development of community-based services requires both a political and a social approach, and consists of policy measures for making all public services, such as housing, education, transportation, health care, and other services and support, available and accessible to persons with disabilities in mainstream settings. Persons with disabilities must be able to access mainstream services and opportunities and live as equal citizens.

Community-based services should be in place to eliminate the need for special and segregated services, such as residential institutions, special schools, long-term hospitals for health care, the need for special transport because mainstream transport is inaccessible, and so on.

Personal Assistance

Personal Assistance is a tool which allows for independent living. Personal assistance is purchased through earmarked cash allocations for persons with disabilities, the purpose of which is to pay for any assistance needed. Personal assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to persons with disabilities need to be in line with the current salary rates in each country.

Persons with disabilities must have the right to recruit, train, and manage their assistants with adequate support if they choose, and they should be the ones that choose the employment model which is most suitable for their needs. Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs, and peer support for the person who needs assistance.

Convention on the Rights of the Child (CRC)

The Convention on the Rights of the Child is a human rights treaty adopted in 1989 by the United Nations General Assembly. It sets out the civil, political, economic, social, health, and cultural rights of children. The Convention is the most widely ratified human rights treaty in the world: all UN Member States except for the United States of America have ratified the Convention. The UN Committee on the Rights of the Child monitors compliance with the Convention. In 2006, the Committee issued General Comment 9, which interprets the rights of children with disabilities under the Convention, including their right to education.

Convention on the Rights of Persons with Disabilities (CRPD)

The Convention on the Rights of Persons with Disabilities is an international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities.

Adopted on 13 December 2006, the Convention requires those states which have ratified it to promote, protect, and ensure the full enjoyment of human rights and fundamental freedoms by persons with disabilities and to ensure that persons with disabilities enjoy full equality under the law. The Convention follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as “objects” of charity, medical treatment, and social protection towards viewing persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions about their lives based on their free and informed consent, as well as being active members of society.

As of July 2020, the Convention has 163 signatories and 182 parties, which is comprised of 181 states and the European Union. The Committee on the Rights of Persons with Disabilities monitors its implementation.

Committee on the Rights of Persons with Disabilities (CRPD Committee)

The Committee on the Rights of Persons with Disabilities is the body of independent experts which monitors implementation of the Convention on the Rights of Persons with Disabilities by states which have ratified it, which are known as States Parties to the treaty. All States Parties are obliged to submit regular reports to the Committee on how the rights guaranteed in the Convention are being implemented. The Committee examines each report and makes such suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the State Party concerned. The Optional Protocol to the Convention gives the Committee competence to examine individual complaints with regard to alleged violations of the Convention by States Parties to the Protocol.

Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW)

The Convention on the Elimination of all Forms of Discrimination Against Women is an international treaty adopted in 1979 by the United Nations General Assembly. Described as an international bill of rights for women, it consists of a preamble and 30 articles that define what constitutes discrimination against women and sets up an agenda for national action to end such discrimination. The Convention provides the basis for realising equality between women and men through ensuring women’s equal access to, and equal opportunities in, political and public life, as well as education, health, and employment. The Convention has been ratified by 189 states and the Committee on the Elimination of Discrimination against Women monitors its implementation.

Sustainable Development Goals (SDGs)

The Sustainable Development Goals are a universal call to action to end poverty, protect the planet, and improve the lives and prospects of everyone, everywhere. The 17 Goals were adopted by all UN Member States in 2015, as part of the 2030 Agenda for Sustainable Development which set out a 15-year plan to achieve the Goals. They recognise that ending poverty must go hand-in-hand with strategies that build economic growth and address a range of social needs including education, health, social protection, and job opportunities, while tackling climate change and environmental protection.

Disability is referenced in various parts of the SDGs and specifically in parts related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and monitoring of the SDGs.

United Nations (UN)

The United Nations is an intergovernmental organisation founded in 1945 and is currently made up of 193 Member States. The mission and work of the United Nations are guided by the purposes and principles contained in its founding Charter. The United Nations aims to maintain international peace and security, develop friendly relations among nations, and achieve international cooperation on issues such as climate change, sustainable development, human rights, humanitarian and health emergencies, gender equality, etc. The United Nations System includes a multitude of specialised agencies, such as the World Health Organization, UNESCO, and UNICEF.

World Health Organization (WHO)

The World Health Organization is a specialised agency of the United Nations responsible for international public health. Established in 1948, the World Health Organization works with 194 Member States, across six regions, and from

more than 150 offices. Its goal is to ensure universal health coverage, protection from health emergencies, and better health and well-being to people worldwide. It has a particular goal in leading global efforts to international public health emergencies, including COVID-19.

UNICEF

UNICEF is a specialised agency of the United Nations responsible for saving children's lives, defending their rights, and helping them fulfil their potential, from early childhood through to adolescence. UNICEF works in over 190 countries and territories.

National Human Rights Institutions (NHRIs)

National Human Rights Institutions are state-mandated bodies, independent of government, with a broad constitutional or legal mandate to protect and promote human rights at the national level. NHRIs address the full range of human rights, including civil, political, economic, social, and cultural rights.

National Preventive Mechanisms (NPMs)

National Preventive Mechanisms are the national component of the preventive system established by the Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT). They are mandated to conduct regular monitoring visits to all types of places where persons are deprived of liberty. Through these visits, NPMs are in a good position to identify early warning signs, and therefore prevent abuse. These torture prevention bodies need to be independent, free from government influence, and provided with sufficient resources to carry out their work effectively. They must also have the power to access all places of detention, without restriction.

Coordinating organisations

The Validity Foundation – Mental Disability Advocacy Centre is an international non-governmental human rights organisation which uses legal strategies to promote, protect and defend the human rights of persons with intellectual disabilities and persons with psychosocial disabilities in Europe and Africa. Validity holds special consultative status with the United Nations' Economic and Social Council (ECOSOC) and participatory status at the Council of Europe.

www.validity.ngo 



The European Network on Independent Living (ENIL) is an international network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross-disability and self-determination.

www.enil.eu 



The International Disability Alliance (IDA) is an Alliance of 14 global and regional organisations of persons with disabilities. Together, the IDA Members promote the rights of persons with disabilities across the United Nations' efforts to advance human rights and sustainable development. IDA supports organisations of persons with disabilities to hold their governments to account and advocate for change locally, nationally and internationally.

www.internationaldisabilityalliance.org 



Disability Rights International (DRI) is a human rights advocacy organization dedicated to the protection and full community inclusion of children and adults with disabilities worldwide. DRI documents human rights violations, educates and engages the public through media campaigns, trains and supports activists working to bring change, and conducts strategic litigation to enforce the rights of people with disabilities. DRI's Worldwide Campaign to End the Institutionalization of Children is dedicated to promoting the recognition and enforcement of the right of all children to live and grow up with a family and not in any form of institution, orphanage, or group home. DRI is an organization led by people with disabilities and their families.

www.driadvocacy.org 



The Disability Rights Unit at the Centre for Human Rights, University of Pretoria, is committed to finding evidence-based ways of addressing the rights of persons with disabilities on the African continent. This includes conducting research on international disability rights standards and instruments, building capacity among governments, national human rights institutions, academia, civil society of people with disabilities, and communities, and engaging with judicial, quasi-judicial and non-judicial redress mechanisms.

www.chr.up.ac.za/units/disability-rights-unit 



The International Disability and Development Consortium (IDDC) is a global consortium of 31 disability and development non-governmental organisations (NGOs), mainstream development NGOs and representative organisations of persons with disabilities (DPOs) supporting inclusive international development and humanitarian action with a special focus on the full and effective enjoyment of human rights by all people with disabilities in more than 150 countries around the world.

www.iddcconsortium.net 



The **Disability Rights Fund (DRF)**, and its sister organization, the **Disability Rights Advocacy Fund (DRAF)**, are pooled funds and participatory grantmakers, bringing together global disability rights activists and donors to resource organizations of persons with disabilities across Africa, Asia, Pacific and Caribbean to advocate for advancement of the Convention on the Rights of Persons with Disabilities (CRPD) at national and local levels. With more than 50% of grants supporting organizations of persons with disabilities marginalized within the disability movement, DRF supports persons with disabilities around the world to build diverse movements, ensure inclusive development agendas, and achieve equal rights and opportunity for all. DRAF supports work to advance legal frameworks to realize rights.

www.disabilityrightsfund.org 

www.drafund.org 



For more information about the work of
the COVID-19 Disability Rights Monitor visit
www.covid-drm.org
